A STUDY ON EXPLORATION OF AWARENESS, BELIEFS AND BARRIERS TOWARDS ORGAN DONATION AMONG PEOPLE IN KUMARAPALAYAM

A Dissertation submitted to

THE TAMIL NADU DR. M.G.R. MEDICAL UNIVERSITY,

CHENNAI- 600 032

In partial fulfillment of the award of the degree of

MASTER OF PHARMACY

IN

Branch-VII –PHARMACY PRACTICE

Submitted by

Name: SURULIVELU. V

REG. No: 261440220

Under the Guidance of

Dr. N. VENKATESWARAMURTHY, M. Pharm, Ph.D.,

DEPARTMENT OF PHARMACY PRACTICE

J.K.K. NATTRAJA COLLEGE OF PHARMACY

KUMARAPALAYAM – 638183

TAMILNADU.

OCTOBER – 2018

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EVALUATION CERTIFICATE

This is to certify that the dissertation work entitled **"A Study On Exploration Of Awareness, Beliefs And Barriers Towards Organ Donation Among People In Kumarapalayam"** submitted by the student bearing **Reg. No: 261440220** to **"The Tamil Nadu Dr. M.G.R. Medical University"**, Chennai, in partial fulfillment for the award of Degree of **Master of Pharmacy** in Pharmacy Practice was evaluated by us during the examination held on……

Internal Examiner **External Examiner**

CERTIFICATE

This is to certify that the dissertation **"A Study On Exploration Of Awareness, Beliefs And Barriers Towards Organ Donation Among People In Kumarapalayam"** is a bonafide work done by **Reg.No.261440220 J.K.K. Nattraja College of Pharmacy**, in partial fulfillment of the University rules and regulations for award of **Master of Pharmacy** in **Pharmacy Practice** under my guidance and supervision during the academic year 2017-2018.

Dr. R. Sambath Kumar, M.Pharm, Ph.D.,

Principal

Dr. N. Venkateswaramurthy, M.Pharm, Ph.D.,

Guide & HOD

CERTIFICATE

This is to certify that the work embodied in this dissertation en titled **"A Study On Exploration Of Awareness, Beliefs And Barriers Towards Organ Donation Among People In Kumarapalayam",** submitted to "**The Tamil Nadu Dr. M.G.R. Medical University**", Chennai, in partial fulfillment to the requirement for the award of Degree of **Master of Pharmacy** in **Pharmacy Practice**, is a bonafide work carried out by **Mr. SURULIVELU. V, [Reg.No.261440220]** during the academic year 2017-2018, under the guidance and supervision of **Dr. N. Venkateswaramurthy, M.Pharm, Ph.D.,** Professor and Head, Department of Pharmacy Practice, J.K.K.Nattraja College of Pharmacy, Kumarapalayam.

Place: Kumarapalayam
Date:

Dr. R. SAMBATH KUMAR, M.Pharm, Ph.D.,
Professor& Principal,
J.K.K.Nattraja College of Pharmacy.
Kumarapalayam-638 183.
Tamil Nadu.

CERTIFICATE

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Place: Kumarapalayam
Date:

Dr. N. VENKATESWARAMURTHY, M.Pharm, Ph.D.,
Professor & Head,
Department of Pharmacy Practice,
J.K.K.Nattraja College of Pharmacy,
Kumarapalayam-638 183,
Tamil Nadu.

DECLARATION

I do hereby declared that the dissertation **"A Study On Exploration Of Awareness, Beliefs And Barriers Towards Organ Donation Among People In Kumarapalayam"** submitted to "**The Tamil Nadu Dr. M.G.R Medical University"**, Chennai, for the partial fulfillment of the degree of **Master of Pharmacy** in **Pharmacy Practice,** It is a bonafide research work has been carried out by me during the academic year 2015-2016, under the guidance and supervision of **Dr. N. VENKATESWARAMURTHY, M.Pharm, Ph.D.,** Professor, Department of Pharmacy Practice, J.K.K. Nattraja College of Pharmacy, Kumarapalayam.

I further declare that this work is original and this dissertation has not been submitted previously for the award of any other degree, diploma, associate ship and fellowship or any other similar title. The information furnished in this dissertation is genuine to the best of my knowledge.

Place: Kumarapalayam **SURULIVELU. V**

Date: **Reg.no: 261440220**

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Mr. SURULIVELU. V

Reg.no: 261440220

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1. INTRODUCTION

Organ Donation-An Overview of the Field[1]

Why Are Transplants Needed?

People need transplants because an organ that they need to continue living is failing to function. Many diseases and conditions can lead to end-stage organ failure. For example, diabetes and hypertension can result in kidney failure. Liver failure can be caused by acute or chronic hepatitis, cancer, or alcohol abuse. Hypertension, congenital disorders, and valvular heart disease can lead to heart failure. Lung failure can result from chronic obstructive pulmonary disease and/or pulmonary hypertension. In addition to enhancing the quality of life, transplantation can give many years to a recipient who otherwise would have died. Immunosuppressive drugs and technological advances have improved recipient longevity: 80.6% of patients who received a deceased donor kidney in 2000 were still living 5 years later, as were 73.6% of liver and 74.4% of heart recipients.[2] Quality of life is also enhanced by tissue transplantation. Corneas give vision to a blind person. Ligaments restore mobility. A heart valve replacement restores function to a defective heart. Skin can repair burns and scars. Bone mends a broken or malformed jaw. In all, more than 900,000 tissue transplants are performed each year.[3] The benefits of each transplant procedure extend beyond providing a new life for the organ recipient; transplantation affects families, friends, colleagues, and others. Considering that one deceased organ donor can potentially save nine lives and improve 50 or more lives with donated tissues. Anecdotal and reported evidence[4] indicates that, besides benefits to recipients and their families and friends, organ donation and transplantation help the donors' surviving loved ones. Knowing that their loved one's gift saved or enhanced the life of even one other individual provides comfort to the bereaved. They can appreciate and treasure the thought that something positive resulted from an otherwise traumatic situation, creating a legacy for their loved one. Despite its far-reaching benefits, transplantation is not available to all

who need it. The potential of this life-saving procedure is limited by an insufficient supply of donated organs. As of August 2009, nearly 103,000 patients were on the national waiting list for organs.[5] However, the total number of deceased donors in 2008 was 7,984. In 2008, 14,198 living and deceased donors enabled 27,958 transplants to occur but another 6,782 patients died waiting for an organ. The donor shortage is simultaneously simple and complex. The simplicity lies in that it is easily identified as the most crucial problem in transplantation today. It is complex due to the need to understand the attitudes, beliefs, and motivation that prevent people from committing to be donors, and to identify, implement, and rigorously evaluate strategies to combat those barriers and increase public donor enrolment.[6,7]

What Can Be Donated?

Organs and tissues can be donated from deceased donors and in rare cases tissues are also donated by living individuals. Deceased donors can provide more organs and tissues than living donors can.[5] Not everyone who dies, however, is eligible to donate. Only deaths that occur in a hospital where organs can be kept viable by artificial means may be considered for organ donation. Tissues and corneas can be obtained from deaths that occur both inside and outside the hospital setting. Some health conditions may preclude donation. The organs that can be donated by deceased donors are kidney, heart, lung, liver, pancreas, and small bowel (small intestine) and tissues that can be provided by deceased donors includes bone, skin, corneas, middle ear, heart valves, veins, cartilage, tendons, and ligaments. Unlike organs, most tissues can be stored and used when needed. Living donors can provide a kidney or a lobe (section) of a lung or a liver. When a liver lobe is donated, the donor's liver regenerates quickly regaining its original size. When a living donor provides a kidney, the remaining kidney will increase in size and perform about 80% of the function of two kidneys. Tissues that can be donated by living donors include amnion after childbirth, skin after

certain surgeries (e.g., abdominoplasties), and bone after hip or knee replacements.

Deceased Donation:

Deceased donation takes place in a hospital after an individual has been declared dead. An important point to remember is that the team of medical professionals trying to save an individual's life in the hospital differs from the transplant team. The former has one goal, to save that life. When all possible attempts have been exhausted and death is imminent or declared, the hospital notifies the local organ procurement organization (OPO) while continuing to mechanically oxygenate the organs pending consideration for donation.

OPO professionals determine whether the deceased is medically suitable to be a donor and obtain consent for donation. A transplant team may not recover organs without legal consent, which is obtained in one of two ways. In states that practice first-person consent, the deceased's predeath designation as a donor serves as legal consent authorizing the transplant team to proceed. Common tools for indicating one's predeath donor designation are donor registries and driver's licenses. In states where first-person consent is not practiced or where a preauthorization tool, such as a driver's license, is unavailable, OPO staff must obtain consent from next of kin.[5] Once consent is obtained, OPO professionals let the surgeons and other recovery team members know that there is a donor. The OPO submits critical information about the donor (e.g., blood type, height, weight, gender, and age) to the Organ Procurement and Transplantation Network (OPTN), the national system that facilitates organ matching and allocation administered by the United Network for Organ Sharing (UNOS) under contract to the U.S. Department of Health and Human Services. The donor's information is entered into the OPTN computer system which contains the same type of information for each wait-listed patient. The computer identifies compatible patients and generates a "match list" prioritizing patients for each donated organ. Patients who are to receive the organs are notified by their transplant

team that an organ is available and told when to go to their hospital to prepare for surgery. Transplant surgeons remove the donor's organs in an operating room under standard sterile surgical conditions. OPOs prepare each organ for transport according to standard preservation procedures for that organ and arrange for ground or air transportation of viable organs to appropriate transplant hospitals. Surgical teams then implant the organs into the intended recipients.

Living Donation

During the past 15 years, living donation has become an increasingly frequent alternative to deceased donation.[5] In the majority of cases, each donor provides one organ: a kidney or a lobe of a lung or liver. Some organs, such as the heart and a set of lungs, can be provided only by deceased donors. In 2001, the number of living donors (6,610) surpassed the number of deceased donors (6,080) for the first time and continued to outpace deceased donation until 2004. Despite a recent downturn, living donation remains a viable alternative. Several factors have contributed to the increase in living donation: the expanding gap between the number of patients needing a transplant and the number of deceased donors, greater public awareness of living donation, and an increase in laparoscopic (camera-assisted) surgeries. Before laparoscopy, removal of a kidney involved a major incision partially around the donor's abdominal area and an extended and uncomfortable recovery period. Laparoscopic kidney recovery requires a few small incisions and a substantially shortened and easier recovery.

Advantages of Living Donation

The availability of a willing and medically suitable living donor offers several advantages for a recipient. Most notably, the recipient is assured of receiving a life-saving transplant. Moreover, because the organ spends less time outside the body (ischemic time), its integrity is better maintained. Also, recipients with living donors can usually be transplanted sooner thereby increasing the likelihood of a successful

outcome. These patients do not have to be wait-listed for an organ and endure the mental anguish of wondering whether an organ will become available. Also, by the time an organ becomes available, the potential recipient might be too sick to with-stand the transplant surgery and recovery process. Lastly, wait-listed patients may die before an organ becomes available; more than 6,000 per year usually do. In addition to helping recipients, living donors themselves experience benefits. [8] Most living donors are relatives or close friends of recipients and generally express gratification in being able to, literally, give of themselves to save a loved one's life.

Risk to Living Donors

Major surgery has potential risks, such as those associated with anaesthesia or surgical error. Surgery to remove an organ for transplant is no exception.[9] Donors electively subject their body to a major surgical procedure with no physiologic benefit for themselves. The transplant field has only begun tracking living donors over time, so potential long-term consequences for living donors are unknown.[5]

Becoming a Living Donor

Once someone decides to become a living donor, a meeting is arranged with the transplant team for physical and psychological evaluation. Only individuals in good health are considered. High blood pressure and diabetes are two disease state that are excluded donors.[5] The psychological evaluation is for the donor's safety—making sure donors have thought through the commitment, understand risks and benefits, and are not being coerced into the procedure.

Living Donation: Obstacles and Options

Not all patients pursue living donation. Patient obstacles include lack of awareness of living donation, reluctance to ask relatives and friends to be donors, and the difficulty of finding a matched donor. Various outreach efforts have been created to overcome these obstacles including programs

to educate dialysis patients of their opportunity for living donation and to help them develop the ability to broach the issue with others.[10] Another strategy is called paired exchange. This involves a group of potential recipients and their willing but incompatible donors. Within the group of pairs, there must be one matching donor for each potential recipient, which allows each recipient to receive an organ from the donor in the group who is a match. Paired exchanges occur among any number of donor–recipient pairs and can involve any combination of relatives or nonrelatives as long as each pair contains a donor and a recipient and every recipient gets an organ.

Organ transplantation: historical perspective and current practice[11]

A brief history of transplantation

Kidney transplantation

Since Jaboulay and Carrel developed the techniques required to perform vascular anastomoses at the turn of the last century, there has been a desire to treat organ failure by transplantation. Jaboulay was the first to attempt this in 1906, treating two patients with renal failure by transplanting a goat kidney into one and a pig kidney into the other; in both cases, he joined the renal vessels to the brachial vessels.[12] Both transplants failed and both patients died. At that time, there was no alternative to death if renal failure developed, and it would be another 38 yr before the first haemodialysis machine was invented. The first use of a human kidney for transplantation followed in 1936 when Yu Yu Voronoy, a Ukrainian surgeon working in Kiev, performed the first in a series of six transplants to treat patients dying from acute renal failure secondary to mercury poisoning, ingested by its victims in an attempt to commit suicide. All the transplants failed, in large part because of a failure to appreciate the deleterious effect of warm ischemia; the first kidney was retrieved 6 h after the donor died.

One limitation to transplantation was the lack of suitable donor organs. The initial pioneers had used animal organs or organs from long deceased humans. In the 1950s, there came a realization of the need to

avoid excessive ischaemic injury and kidneys from live donors began to be used. Some of these were from the relatives of the recipient; others were unrelated patients having a good kidney removed for other reasons. The surgical technique also needed refinement; while a kidney based on the thigh or arm vessels might be technically straightforward, and possibly adequate for the short-term treatment of acute renal failure, it was not a realistic solution for the long term. That solution came from France in 1951 and involved placing the kidney extra-peritoneally in an iliac fossa, where the external iliac vessels are easy to access and the bladder is close by for anastomosis to the donor ureter; this is the technique still used today. Having overcome the technical issues of vascular anastomosis and placement of the kidney, there remained the problem of the immune response. Medawar's work during and after the Second World War studying the rejection of skin grafts had demonstrated the potency of the immune system.[13] At that time, attempts to control the immune system using irradiation had proved either ineffectual or lethal. The first successful transplant therefore came about by avoiding an immune response altogether, which Joseph Murray's team achieved by performing a kidney transplant between identical twins. [14] There then followed a series of identical twin transplants around the world, with the first in the UK being performed in Edinburgh by Woodruff and colleagues[15] in 1960.

Liver transplantation

Success in clinical liver transplantation took longer to realize than kidney transplantation. The recipient is usually much sicker than a renal transplant recipient, and the operation is a more formidable undertaking and is usually performed in the presence of a significant coagulopathy. Initial attempts at liver transplantation in 1963 by Starzl[16] in Denver were unsuccessful, but following a move to Pittsburgh in 1967, his results improved. The first transplant in Europe was performed by Calne in Cambridge the following year.[17] Starzl had preceded his clinical attempts with extensive animal work during which he identified the need

to cool the liver before transplantation and to maintain venous return to the heart using veno-veno bypass to shunt blood from the inferior vena cava (IVC) and portal circulation to the superior vena cava. In spite of these innovations, it would be another two decades, following improvements in patient selection, perioperative management, and postoperative immunosuppression, before liver transplantation could be considered a successful treatment for patients in liver failure.

Heart transplantation

The pioneer in cardiac transplantation was the American surgeon Norman Shumway working in Palo Alto. A series of animal experiments had enabled him to work out the operative strategy, which involved cooling the heart and leaving part of the atria in situ to reduce the number of anastomoses required.[18] However, it was Christiaan Barnard, working in Cape Town and having visited Shumway's unit, who performed the first human heart transplant in 1967.[19] The following year, on the same day that Calne performed the first liver transplantation in the UK, Ross[20] performed the first heart transplant, at the National Heart Hospital in London. During the 12 months after Barnard's transplant, more than 100 cardiac transplants were performed at centres around the world. Results were very poor, with few patients surviving to leave hospital. Over the next decade, only Shumway's group and that of Cabrol in Paris remained active. A key advance was the introduction of endomyocardial biopsy by Caves in 1973 and the classification of histological rejection by Billingham.[21] Only with the introduction of ciclosporin in the early 1980s did cardiac transplantation become widespread. By 1986, more than 2000 procedures annually were being reported to the Registry of the International Society for Heart and Lung Transplantation (ISHLT). A decade later, this had more than doubled, although there has subsequently been a decline from that peak in all parts of the world.[22] UK numbers similarly were at their highest in the mid-1990s, with more than 300 transplants shared between seven centres, but have now decreased to less than half that number. The first

lung transplant was performed by Hardy, in 1964. Although the patient died of renal failure after 3 weeks, the case is notable because the lung was donated after circulatory death (DCD) and early function of the lung was excellent.[23] Progress over the next 15 yr was dogged by airway healing complications and the longest survivor that of Derom in Belgium lived only 6 months. Reitz and colleagues[24] performed the first successful heart–lung transplant in 1981 and the Toronto group achieved successful single lung transplantation a few years later. The bilateral lung transplant, with separate hilar anastomoses, was introduced in 1992[25] and is now the standard procedure for the majority of patients.

Clinical results in organ transplantation

The results of transplantation of all solid organs have improved year on year in spite of the fact that fewer 'ideal' donor organs are used; instead, donors are now older and more commonly donate after a spontaneous cerebrovascular event rather than after isolated traumatic brain injury.

Kidney transplantation

There are around 22,000 patients in the UK alive with a functioning kidney transplant, and a further 25,000 on dialysis, of whom 7000 are active on the kidney transplant waiting list.[26] Figure 2A illustrates the underlying diagnosis in those patients, while Figure 2B illustrates the long-term outcomes after kidney transplantation. As can be seen for all transplant types, there is an initial rapid decrease in graft (and patient) survival in the first few months post-transplant and thereafter a slow attrition; around 70% of grafts will be functioning at 10 yr. The early graft losses include technical problems such as vascular thrombosis, and also losses due to rejection. Late losses are usually a result of a combination of pre-existing donor disease, recurrence of the recipient's own disease (e.g. IgA nephropathy), and immunological response to the graft.

Pancreas transplantation

Most pancreas transplants are performed in patients with diabetic nephropathy who either also require (80%) or who have previously received (15%) a kidney transplant. A small number of patients with life-threatening hypoglycaemic unawareness receive a pancreas alone. In this latter group of patients, their symptoms have to be sufficiently troublesome to warrant a major laparotomy and the continued immunosuppression that is involved. Although the first pancreas transplantation in the UK was in 1978, activity has only increased in the last few years, largely as the result of national commissioning along similar lines to cardiothoracic and liver transplantation. The number of pancreas transplants has increased from around 40 in 2000 to nearly 20010 yr later. The results of pancreas transplantation have improved rapidly as experience accrued, with the most recent results now as good as those in the USA (Fig. 3). A proportion of donated pancreases are processed to extract islets for isolated islet transplantation. This is also indicated for patients with life-threatening hypoglycaemic unawareness, and has the advantage that it avoids a significant surgical intervention. However, the extraction, isolation and transplantation process is not very efficient such that most recipients continue to require insulin afterwards, although they are symptomatically much improved.

Liver transplantation

The most common indication for liver transplantation today is hepatocellular carcinoma (hepatoma) occurring in a cirrhotic liver (Fig. 4A). The hepatoma(s) must be small and confined to the liver; current guidelines indicate that patients with a single tumour under 5 cm or no more than 5 tumours all under 3 cm are suitable candidates with least chance of recurrence or extra-hepatic spread of the tumour. The majority of these hepatomas occur against a background of hepatitis C-induced cirrhosis, which also accounts for 14% of transplants in patients without tumours. Alcoholic liver disease is the next most common indication for liver transplantation. Potential recipients must have abstained from

alcohol for 6 months before listing, a period of time that may allow significant recovery if there is an element of alcoholic hepatitis. Autoimmune disease represents most of the other indications. Hepatitis B, once a common indication for transplantation, now only accounts for 1% of liver transplants, reflecting the impact of the new anti-viral treatments for that disease. It is hoped that the anti-viral drugs against hepatitis C that are currently in development will have a similar effect on the current hepatitis C epidemic.[27] Acute liver failure represents about 10% of transplants performed in the UK. Although such patients are prioritized for a liver via the national allocation scheme, one-third will die before a suitable graft can be identified. After non-urgent liver transplantation, the long-term outcomes are good (Fig. 4B), with a 10 yr patient survival in excess of 60%, and likely to approach 70% for the most recently transplanted patients.

Heart transplantation

In both adult and paediatric practice, the most common indication for transplantation is idiopathic dilated cardiomyopathy (Fig. 5A). Most other paediatric recipients will have complex congenital heart disease and often come to surgery after a number of previous palliative procedures. Problems of pre-sensitization to HLA antigens add to the substantial technical difficulties, and these patients are very challenging. Outcomes have been improving in recent years (Fig. 5B). Across the board, a 1 yr survival of 80–85% can be expected, with a subsequent attrition rate of perhaps 4% annually. Late deaths are most commonly the result of graft vasculopathy. The endothelium of the graft coronary circulation represents the zone of contact between host and recipient. Endothelial dysfunction can be detected as early as 6 weeks post-transplant. It is likely that ongoing immune injury is the stimulus for subintimal thickening that eventually results in diffuse coronary arterial narrowing. Post-transplant rejection episodes, dyslipidaemia, and continued smoking are all predictors of worse disease. In addition, donor age and pre-existing coronary disease are also important. Most other deaths are

the consequence of prolonged immunosuppression, with malignancy and renal failure prominent. Functional outcome is excellent, with very good quality of life and return to normal activities after successful transplantation. Paediatric results have been improving steadily over the past few years, perhaps reflecting the restriction of activity to specialist centres (just two in the UK). In particular, infants presenting with cardiomyopathy may expect a 10 yr survival approaching 90% after transplantation.[28]

Lung transplantation

Major indications for lung transplantation include cystic fibrosis, emphysema, and pulmonary fibrosis (Fig. 6A). The last may be best treated with a single-lung transplant, but the bilateral procedure has become the norm for most patients. There are clear-cut advantages in terms of both early and late survival. Very few combined heart and lung transplants are currently performed, and they are largely restricted to patients with complex congenital heart disease and secondary pulmonary hypertension. There remains a significant early mortality rate (Fig. 6B) which principally relates to primary graft dysfunction and brain-death-induced damage in the donor.[29] As a result, barely 20% of potential donor lungs in the UK are currently used for transplant, and while relaxation of donor criteria may permit greater activity, it may also result in more early graft dysfunction and patient mortality.[30] Although registry figures continue to suggest a 5 yr survival of only 50–60%, single institution results, particularly in favorable groups such as those with cystic fibrosis, can be much better. Median survivals in excess of 10 yr have recently been reported.[31] Late attrition is largely related to progressive small-airway narrowing, termed obliterative bronchiolitis. Although it is, in part, a chronic immune injury, early post-implant damage is also a risk factor, and it would seem that a range of immune and non-immune insults set up progressive airway obliteration. The latter include viral infections and gastro-oesophageal reflux. While in

some patients, augmented immunosuppression may halt the progress, for others re-transplantation is the only option.

Worldwide Barriers to Organ Donation[32]

Racial and Ethnic Considerations

It is possible that cultural and religious perspectives on brain death and organ donation may play a larger role in regional donation rates than any specific legislative guidelines. There are race and ethnicity as well as sex discrepancies between organ donors and recipients, wherein certain groups comprise a small fraction of donors but a much greater percentage of recipients.[33] These racial/ethnic disparities are not unique to the United States. In the United Kingdom, research shows that people of Asian or African-Caribbean descent are 3 to 4 times more likely than white individuals to develop end-stage renal disease and that, while such groups represent only 8%of the population, they form 24%of the waiting list for kidney donations.[34] These disparities can be partially explained by the lack of information offered to different cultural groups about organ donation. Conversely, a higher prevalence of organ failure among certain racial/ethnic groups may preclude organ donation and explain discrepancies in donation compared with transplant receipt rates. Nonetheless, data support the hypothesis that the relatively pervasive negative attitudes toward donation among some racial/ ethnic groups may reflect feelings of marginalization.[35] There is a need for a more nuanced understanding of the interplay of race/ ethnicity, age, socioeconomic status, and area of residence to inform public campaigns and promote sensitive discussions with potential donors and families from different backgrounds.[36]

Religious Considerations

Aside from race/ethnicity, religion plays a key role for many in the decision to become an organ donor. Although all major religions support organ, tissue, and eye donation, within each religion there are different schools of thought. Most religious texts allude to the concept of helping

the needy, which can be extrapolated to organ donation.[37] Currently, there are no data regarding consent rates based on faith principles of the donors and their families. However, many religious groups have released statements relating to their perspectives on organ donation (Table 3). In a multi-cultural world, it is imperative that organ procurement teams, as well as surgical and critical care specialists, receive proper training on cultural and religious sensitivity. Use of multidisciplinary faith based counselling can assist in end-of-life and organ donation conversations.

Organ Trafficking

Globally, legislation guiding organ donation and transplant varies widely.[38] Only 20%of African nations report having a transplant and organ donation coordinating structure, while 95% of countries in the Americas have such a system in place. Even fewer countries have a mechanism for collection and analysis of data related to donation, donor safety, and transplantation activities. Some countries report that liver and/or kidney transplants are performed despite a lack of legislation. Such lack of over sight may promulgate illegal transplantation and organ trafficking. Even in countries that have legislation regulating organ trafficking, there is weak enforcement and few international regulations that can effectively police the problem.[39] A recent report by Global Financial Integrity estimates that the illicit organ trade generates illegal profits between $600million and $1.2 billion per year.[40] It is hypothesized that this market is fuelled not only by profit but also by cultural and religious barriers to organ donation and transplantation in some countries, long waiting lists for organs, precarious infrastructure for transplants in the country of origin, and difficult access to chronic life support (in the case of renal replacement therapy).[41] A growing number of countries report that patients have allegedly travelled to countries to buy organs on the black market, a practice known as *transplant tourism*. The World Health Organization estimates that 5% to 10% of kidney transplants worldwide occur as a result of commercial transactions.[42,43] A study of American citizens who received organ transplants abroad

showed that roughly 90% were kidney transplants and that male sex, Asian race, resident and non-resident alien status, and college education were significantly and independently associated with foreign transplant.[44] In 2006, patients from 34 states, plus the District of Columbia, received foreign transplants in 35 countries, led by China, the Philippines, and India. In contrast to commercial organ recipients, commercial donors tend to be under privileged. In a survey of 239 kidney vendors in Pakistan, it was reported that 90% of the donors were illiterate and 70% were bonded laborers. Although the money for organ donation had been accepted primarily to repay debts, 88%reported no financial improvement in their lives after nephrectomy and many expressed substantial regrets.[45] The mean (SD) compensation for living kidney donation was $1377 ($196) after deduction for hospital and travel expenses. Unfortunately, the outcome from such transplants is poor both for donors and recipients. Up to 98%of donors reported deterioration in their general health status after nephrectomy.[45] The care for the commercially transplanted organ recipient is also precarious, as articles show high rates of infections and insufficient use of immunosuppressants[46] as well as significantly worse patient and graft survival rates at 3 years.[47] Some progress has been made in battling organ trafficking. One strategy supported by the World Health Organization is to help governments Implement DCD programs to increase donation rates and achieve self-sufficiency.[48] In China, some progress has been made regarding the access of foreigners to transplants;[49] however, the use of organs from executed prisoners for transplantation purposes continues despite widespread condemnation.[50] Recently, Canadian authorities have proposed the implementation of financial incentives for living organ donation in an attempt to decrease both organ trafficking and the national organ wait list.[51] One study using decision analysis modeling hypothesized that, with the current organ donation system, a strategy of increasing the number of kidneys for transplantation by 5% by paying living donors $10 000 has an incremental cost savings of $340 per patient and a gain of 0.11 quality-

adjusted life years.[52] Financial incentives could be a possible solution to decrease organ trafficking and may concurrently increase donations, but several ethical concerns remain, namely that incentivized donation could affect the donor population of non–financially compensated donors, the standardized waiting list process could be corrupted, and exploitation of low-income donors could occur. Recently, a more satisfying solution has been proposed by the Convention against Trafficking in Human Organs.[39] The main objectives of the convention are to promote international cooperation in the investigation and prosecution of organ traffickers, to develop measures to prevent trafficking, and to protect exploited victims and witnesses of illegal donation. The convention provides an international legal basis for prosecution of organ brokers, corrupt officials within organ donation systems, health care professionals, and physicians who participate in commercialized transplant or organ procurement from donors without valid authorization.

Factors that Determine Deceased Organ Transplantation in India[53]

Role of effective communication

Becoming a deceased organ donor is mostly decided by one's next of kin. Lange studied that family members agree to organ donation in over 90% of the cases where family members have some indication of the wishes of the person who has died.[54] Hence, a good communication with family about the intention to donate is a determining factor which changes a potential donor to a real donor after death. A potential donor with ample knowledge and positive attitude toward organ donation is likely to effectively communicate and convince the family members.[55] Hence, the best way to ensure this certainty is to persuade those who are willing to donate organs to discuss the issue with family members. Unfortunately, there appears to be an assumption that simply signing an organ donor card will stimulate family discussion although it is apparent to those working in the area of organ procurement that this is not the case.[56] There is also a larger section among youth who move along with the tide

and accede to this demand and sign donor cards on account of peer pressure and media enthusiasm. These sections are having low knowledge on organ donation and are highly unlikely to stick to their consent and decision. This information is also vital to the creation of future organ donation awareness campaigns.

Organizational support for organ donation

In the initial years of organ donation in India, it was thought that sociocultural, religious, and lack of knowledge on the issue are the only reasons that barred families from giving consent for organ donation, but it was soon apparent that there were many other factors other than these impeding organ donations.[56] The lack of adequate number of transplant centers with inadequate infrastructure and staffs as well as lack of adequate number of trained transplant coordinators is acting as hindrance to the deceased donation program of India.[57,58]A study has also reported that about 20% of nephrologists from India have migrated abroad.[59] The high cost of immunosuppressive agents, poor maintenance of dialysis programs, absence of research, lack of national health insurance programs that cover patients undergoing transplantation, lack of coordination between various medical units, etc., are posing challenges to India's deceased donation program.[58] In many hospitals in India, there are no clear protocols to certify brain deaths. Many hospitals do not have the adequate institutional mechanisms to approach and take consent from families of brain dead patients.[56]

Legal and ethical issues

There are many ethical issues and loopholes within "The Transplantation of Human Organs Act" (THOA) which acts as another determining factor in organ donation. There are issues regarding consent, incentives to donors and families and equitable distribution of donated organs.[56] The law which says about unrelated live donation has high likelihood to get misused and is an important reason why kidney trade still exists in India.[60,61] The THOA failed to prevent the commercialization of organ

donation as it was before the implementation of the act and was also not able to increase the number of deceased donors to take care of organ shortage existing in the country.[62,63] Even though there are many issues and concern with the act, it was the first step in the right direction. A strong legislation will not be sufficient enough to improve the organ donation scenario in India. There may be other factors that determine organ donation. Even though the government has come up with a national registry to streamline and centralize the process, it is still not fully active and operationalized. Here, it is the prevalent mode of inertia in the administrative and government setups in India acting as the bottleneck.

Negative propaganda by print and digital media on organ donation

Cadaveric organ donation is built upon predominantly by altruism and public trust. If anything shakes that trust, everyone loses the hope in the whole process of organ donation. The print and social media are a prerequisite in today's world to promote organ donation but there are many which also propagate negative propaganda particularly on the financial gains of the hospitals/institutions without any evidence. This phenomenon has been on the rise recently, and it may act as a deterrent to organ donation.

Financial issues

Last but not the last, an important hurdle is the financial incompetency of many poor recipients. Nowadays, it is a common feature in newspapers and roadside hoardings to see request for help to the poor patients who are awaiting transplantation. In India, especially for the poor, most of the transplantations are achieved through social contributions and not necessarily government funds. Apart from this, there are multiple factors that affect live organ donation in India, but the relative influence is different for cadaveric versus live donation. All the actions to improve the organ donation scenario should hence be directed toward factors that are

most vital in elucidating the present variation in willingness for donation.[64]

Necessity of organ donation in India

Globally and nationally, there is an urgent need to promote organ donation since there is an acute mismatch between the organs donated and people in queue for transplantation. Every day, a number of people are dying while waiting for an organ transplant. It has been now estimated that in India, only 2.5% of patient with end-stage renal disease finally end up getting a transplant.[65] While 2.1 lakhs Indians have need of kidney transplantation every year, the actual cases which happens are ranging from 3000 to 4000.[66] While 12 lakhs Indians require a corneal transplant every year, about 45,000–50,000 eyes are only collected every year by efforts from all eye banks operating in the country.[67] It is also to be noted that compared to renal dialysis, transplant leads to a longer and quality life.[68] Transplantation is also more cost-effective than renal dialysis.[69]

Cadaveric donation: the way ahead

An unswerving cadaveric or deceased organ donation program is seen by many experts as the only viable and sustainable solution to the problem of organ shortage in India. Cadaveric donation refers to transplantation of organs from a brain dead person to a recipient. Brain death refers to the irreversible loss of all functions of the brain, including the brainstem. It is different from coma or vegetative state where the brain is still functioning. Unlike to living donation, the deceased organ donation program has the potential to transplant heart, kidneys, liver, lungs, pancreas, small intestine, larynx as well as tissues such as heart valves, corneas, and bone marrow. The prospective for cadaveric donation is high in India due to the vast number of road traffic accidents occurring annually. The road traffic accidents accounts for around 1.4 lakhs death in India annually. Among this, 65% sustain severe head injuries according to a study conducted by AIIMS, Delhi. Hence, it can be

assumed that around 90,000 cases will befall in the "brain dead" category.[66] If we are able to tap this, by promoting cadaveric donation, India can be the global leader in deceased organ donation. Hence, all the future efforts in promoting organ donation in India should primarily focus on cadaveric donation programs. The stigmas and misconceptions surrounding this issue can be removed only through awareness programs. Since the issue has a clear religious overtone, there should be a concerted effort to rope in organizations that have a say in such matters to address the issue. A simple fact is that almost all organs in a cadaver can be transplanted in a living body within prescribed conditions of time limit. Hence, there is also a need to further rationalize the process through innovative methods and techniques. Research in this regard is another frontier into which the country has not ventured into so far, vigorously. Hence, government should allocate funds for new medical researchers in organ transplantation. The concept of organ donation should reach the public and the role of various stakeholders is pivotal in this process. The government, NGOs, medical fraternity, media, and youth organizations should join hands for this endeavour. The loopholes in the law should be rectified and administrative bottlenecks should be reduced from the government side. The infrastructure in government and private hospitals to conduct transplantation should be strengthened. Various awareness programs such as continuing medical education programs among medical and paramedical personnel, transplant counsellors and coordinators should be done. The "standard operating procedures" established to identify and certify brain death, maintain and transport organs, and tackling medico-legal cases should be uniform and standardized in both government and private hospitals. Since lack of uniformity may pave way for malpractices. To propagate organ transplantation in a big way, we have to enlist support from various stakeholders on priority basis. Doctors have their role in facilitating this. However, the medical students have the added responsibility to carry out the meaningful propagation of this noble mission. There should be a systematic evaluation of the doctors' knowledge and commitment to this

concept. We should inculcate these ideas of life-giving and life-extending measures in the medical curriculum as well as in school curriculum to promote organ donation.

2. LITERATURE REVIEW

Bharambe VK et al., (2018)[70] conducted a study to assess the attitude and knowledge toward body and organ donation among people in rural India. A questionnaire covering demographic data, knowledge, and attitude of the participants was distributed to 400 students, middle-aged and senior citizens; 91.5% of the respondents were aware about organ donation. Television (55.2%) and newspaper (45.8%) were the most popular sources of information. About 56.2% and 32.8% believed that a healthy person and a cardiac dead person can be donors, respectively. Nearly 29.4% believed that a brain-dead person can be a donor and 22.4% clearly stated as to be having no idea regarding the health status of a donor. Highest awareness was observed regarding eye donation (92%). High awareness was also observed regarding heart, kidney, and liver donations, that is, 71.1%, 61.2%, and 54.2%, respectively. Awareness regarding donation of other tissues and organs was poor. Only 46.8% believed that the family of the deceased person can give consent for organ donation if the donor had not signed the donor card. Awareness regarding both body and organ donation in rural India is high. However, there is lack of understanding regarding the concept of brain-death. Awareness regarding body and other organ and tissue donations besides eye, kidney, etc., needs further awareness drives.

Poreddi V et al., (2017)[71] has conducted a cross-sectional descriptive study was carried out among randomly selected patient relatives (n = 193) at the outpatient department of a tertiary care center to assess gender differences in the perceptions and attitude of general population toward organ donation. Data were collected through face-to-face interview using a structured questionnaire. Our findings revealed that majority of men than women were aware and in favor of promoting organ donation ($x2 = 10.428$, $P < 0.001$). Best part of men (70.9%) compared to 52.3% of women were willing to donate their organs after death ($x2 = 18.080$, $P <0.001$). Similarly, more number of (48.5%) men were willing to

sign on the organ donation card. There is an urgent need to uncover the myths and misconceptions of the general population toward organ donation. Further, healthcare providers and governmental and nongovernmental agencies should take active initiation in motivating the public to give their consent for organ donation.

Sebastian-Ruiz MJ et al., (2017)[72] has conducted protective, descriptive, observational, and cross-sectional study to evaluate the knowledge and attitude towards organ donation of medicine students of a Northwestern Mexico public university. 74% of students would donate their own organs, mainly due to reciprocity (41%). 26% of students would not donate, 48% of them because of fear that their organs could be taken before death. 86% would donate organs from a relative. 64% have spoken about organ donation and transplantation with their family and 67% with friends. 50% said they had received no information about it. 68% understand the concept of brain death. The study concluded that the students received little information about organ donation during college. Despite that, most of them showed a positive attitude and are willing to donate.

Ibrahim M et al., (2017)[73] has conducted a cross-sectional study among Nigerian international students of the University. Out of the 110 questionnaires distributed, 103 were returned fully completed (response rate = 93.6%). A significant majority (93.2%) of the participants are aware of organ donation, and 76.7% have a good knowledge on the subject. Furthermore, more than half (52.8%) of the participants have a positive attitude toward organ donation, and less than half (42.8%) have favorable behavior toward it. Higher knowledge does not correlate to either positive attitude or behavior, but a positive attitude is correlated with favorable behavior toward donation. The attitudes and behavior of the respondents toward organ donation is not commensurate with the level of knowledge they possess. This highlights the urgent need for well-structured educational programs on deceased organ donation.

Hejazi SS et al., (2017)[74] has conducted a cross-sectional study was conducted from March to September 2014, to determine the knowledge and attitudes of citizens of Bojnurd toward brain death and organ donation Three hundred and eighty participants with the average age of 29.91±9.32 were studied, of which 55% were female. The average score of awareness and attitude was 11.42 (±2.40) and 39.8 (±6.01) respectively. The awareness of the majority of the people (63%) regarding organ donation was moderate and the attitude toward organ donation in the majority (74.1%) was poor. In people with poor attitudes, awareness was also lower, and this was statistically significant (p=0.047).the attitude towards organ donation was negative in the majority of the citizens. In order to correct the beliefs, develop positive attitude and increase citizens' knowledge, public education is essential.

Agrawal S et al., (2017)[75] has conducted a hospital-based cross-sectional study to assess the knowledge and attitude of the adult population toward organ donation in Saudi Arabia. Where the information was collected using a self-administered questionnaire in Al-Kharj, Saudi Arabia. The questionnaire was distributed in both King Khalid Hospital and Prince Sattam Bin Abdulaziz University Hospital, and data gathered analyzed by Statistical Package for Social Sciences (SPSS version 20.0). There were a total of 403 respondents. Nearly 35.6% did not have the knowledge that organ donation is legal in the KSA. Almost 97% did not know where to go if they want to become donors. All of who were willing to donate, the most common reason was to save someone's life (92.7%). Body distortion (39%) and fear of health complications (35%) were the most common causes people opposed donation. It was suggested that, in order to increase the awareness for organ donation, the important role of health workers and hospital displays should be immediately addressed and public lectures should be held on regular basis.

Vijayalakshmi P et al., (2016)[76] has conducted a cross-sectional descriptive study to evaluate the rate of organ donation in India is low and research on organ donation among the general population is limited. They assessed the knowledge, attitude and willingness to donate organs among the general population. We found that 52.8% of the participants had adequate knowledge and 67% had a positive attitude towards organ donation. While 181 (93.8%) participants were aware of and 147 (76.2%) supported organ donation, only 120 (62.2%) were willing to donate organs after death. Further, there were significant associations between age, gender, education, economic status and background of the participants with their intention to donate organs. Our study advocates for public education programmes to increase awareness among the general population about the legislation related to organ donation.

Yazar MA et al., (2016)[77] has conducted a descriptive study to determine the knowledge levels and attitudes of people living in Nevşehir on organ donation (OD) and transplantation. Four hundred and fourteen people between the ages 20 and 65 years participated. In total, 8.9% of the participants correctly answered the question 'What is necessary for donating an organ?' and 31.4% of them correctly answered the question 'What is brain death?' Moreover, 53.1% of the participants stated that they wanted to receive reliable information on OD from OD centres. There was a close relationship between high education level and the willingness to donate organs ($p<0.05$). Further, 94.7% of the participants stated that they did not want to donate organs: 22.9% of them explained that their decision was because of their religious beliefs and 19.6% stated that their families did not allow it. It was observed that people who accepted organs from others were more willing to donate organs to their relatives ($p<0.05$). People living in Nevşehir do not have sufficient knowledge on OD; they had various concerns on the issue and wanted to receive information from OD centres. Exemplification and internalisation methods can be used in educational schedules to increase the OD.

Luo AJ et al., (2016)[78] has conducted the survey with stratified random sampling. Overall, 600 residents, aged ≥18 who resided in Hunan, and 600 undergraduates from 3 universities in Hunan were surveyed randomly. Of the 1085 participants, 581 (53.5%) were students, 504 (46.5%) were residents, and 519 (47.8%) were male and 566 (52.2%) female. The mean accuracy rate was 71.96%, and the students' mean accuracy rate was slightly higher than that of the resident population (73.06% vs 70.68%, respectively). The results showed that 82.2% of public support organ donation, and 53.5% were willing to donate their organs after death. Students scored higher than the residents (88% vs 75.6% and 55.6% vs 51.2%). Nearly 1.8% felt that organ donation was against their religion, 14.9% thought it was important to ensure the integrity of the body, 71.7% agreed that organ donation allowed a positive outcome after a person's death, and 61.5% agreed that organ donation represented a continuation of life, to help families cope with grief. Age and gender were related to attitudes. Public knowledge of organ donation and their attitudes were correlated positively (r = 0.666) Public knowledge of organ donation is poor, biased, and incomplete, and based on television, movies, and communication networks. Positive attitudes toward donation displayed in the surveys were not matched by actual organ donation.

Bedenko RC et al., (2016)[79] has conducted a questionnaire based study to evaluate the knowledge and acceptance of the public and professionals working in intensive care units regarding organ donation after cardiac death. In total, 543 questionnaires were collected, including 442 from family members and 101 from health professionals. There was a predominance of women and Catholics in both groups. More females intended to donate. Health professionals performed better in the knowledge comparison. The intention to donate organs was significantly higher in the health professionals group (p = 0.01). There was no significant difference in the intention to donate in terms of education level or income. There was a greater acceptance of donation after

uncontrolled cardiac death among Catholics than among evangelicals ($p < 0.001$). Most of the general population intended to donate, with greater intentions expressed by females. Education and income did not affect the decision. The type of transplant that used a donation after uncontrolled cardiac death was not well accepted in the study population, indicating the need for more clarification for its use in our setting.

Panwar R et al., (2016)[80] has conducted a survey to find out the reasons for poor organ donation rates in India. A 30-item questionnaire was designed in the English and Hindi language and was administered to the lay people in order to assess their knowledge, views, and attitude regarding brain death and organ donation. Three hundred and fifty-two people completed the questionnaire. Only 70% of the people were aware that the organs can be donated after brain death and only 44% thought that they understood the meaning of brain death. Media and Internet were the preferred sources for seeking information on brain death and organ donation. The majority of people (81.2%) were willing to donate organs after brain death but only 1.4% had registered for organ donation. Lack of awareness (80.1%), religious beliefs and superstitions (63.4%), and lack of faith in the healthcare system (40.3%) were believed to be the most important reasons for poor deceased organ donation rates in India. The survey also highlighted the importance of the opinion of family members and the religious leaders in making the decision for organ donation. Educational qualification above matriculation was significantly associated with the knowledge of brain death and the willingness for organ donation.

Balajee KL et al., (2016)[81] has conducted a community-based cross-sectional study to assess the awareness and attitudes regarding organ donation among the rural population and to evaluate the sociodemographic factors associated with their awareness. Out of 360 participants, 88% (317/360) were aware of organ donation. Among these 317 participants, awareness was highest in the age group 18-30 years.

Source of awareness about organ donation was primarily through media 83% (263/317). The majority of the participants 88% (281/317) felt that the purpose of organ donation was to save life. Most of the participants 91% (290/317) said that all healthy adults are eligible organ donors and 87% (275/317) of the participants said that monetary benefits could not be accepted for organ donation. Most of the participants 70% (223/317) were willing to donate their organs after death. Among the participants who refused to donate their organs, family refusal 57% (25/44) was the most common reason. This study shows that there is a high level of awareness about organ donation among rural people and most of the participants are willing to donate their organs.

Esqalli I et al., (2015)[82] has conducted the opinion survey in Marrakech city to evaluate the knowledge, attitudes and beliefs of students concerning organ donation and transplantation. Hundred percent of surveyed subjects answered the questionnaire. Among them, 40.3% were men. The middle age was 21.5 years. Out of 503 surveyed students, 89.4% were aware of organ transplant in Morocco. A quarter of students believed that removal and transplant acts were realized just in public health establishments, which have the authorization. Two persons out of 3 were able to identify transplantable organs and tissues. More than half accepted to donate their organs after death. The religious reason was in the head list of refusal determinants of organ donation after death, with a prevalence of 39.7%. Young Moroccans have limited knowledge relating to organ donation. The development of this therapy needs to establish an adequate project of information and motivation of general population.

Balwani MR et al., (2015)[83] has conducted face interviews based on a pre-tested questionnaire in selected public areas of Ahmedabad, Gujarat state of India.to evaluate the attitudes and practices regarding organ donation in western India. About 86% of participants were aware of the term organ donation but knowledge about its various aspects was low. About 48% aware people heard about organ donation through medical

fraternity, whereas only about 21% became aware through mass media. About 59% of aware people believed there is a potential danger of donated organs being misused, abused or misappropriated. Around 97.67% participants said they would prefer to donate to nonsmokers. About 74.41% participants were unaware about any legislation regarding organ donation. About 77% participants showed their will to donate to mentally sound persons, and 42.04% participants showed their will to donate even physically challenged people. Around 78 participants felt that they would donate organs to persons irrespective of their religion. About 81% of aware people were of the opinion that consent for organ donation after death should be given by family members. Better knowledge and awareness will help in promoting organ donation. Effective campaign needs to be driven to educate people with relevant information with the involvement of media, doctors and religious scholars.

Davison SN et al., (2014)[84] has conducted mixed-methods design to describe knowledge of and preferences for organ donation to evaluate Organ donation and transplantation rates are low for aboriginal people in Canada, despite a high demand. Although 83% of participants were in favor of transplantation, only 38% were willing to donate their organs after death, 44% had not thought about organ donation, and 14% did not believe it was important. Only 18.7% of participants reported that their cultural beliefs influenced their views on organ donation and transplantation. In the multivariable analysis, the only factors associated with willingness to donate organs were higher education and considering organ donation important. Willingness to donate organs was lower in these First Nations participants compared to the general population. Education to address knowledge deficits, emphasize the negative impact of organ failure on the community, and contextualize organ donation within the older traditional native beliefs to help First Nations people understand how organ donation may be integrated into native spirituality likely is required to increase donation rates.

Ahlawat R et al., (2014)[85] has conducted self-administered questionnaire for all doctors, paramedical workers, nursing staff and other staff members to evaluate The attitude of healthcare workers towards organ donation can either facilitate or hinder the process of organ donation. The questionnaire completion rate was 99%. About 55% of the study populations were agreeable to donating organs after death and 27% were undecided. The factors that positively influenced their willingness to donate organs after death were favorable attitude of the spouse, religious beliefs supporting organ donation, knowledge of hospital's organ transplant programme, personal experience of the organ donation scenario, having ever donated blood or involvement in social activities, willingness to become an eye donor and willingness to become a living kidney donor. A largely favourable attitude towards organ donation was seen in our study population. However, the study reflects incomplete knowledge leading to confusion and thus, desire to know more among participants with respect to various aspects regarding organ donation. The factors identify that positively influence decisions regarding organ donation can be used as direct interventions.

Kumar V et al., (2014)[86] has conducted a study for assessing deceased donation potential and identifying barriers to its utilization are required to meet needs of patients with organ failure. Over a 6-month period, we identified and followed all presumed brainstem dead patients secondary to brain damage. All patients requiring mechanical ventilation with no signs of respiratory activity and dilated fixed and non-reacting pupils were presumed to be brainstem dead. All events from suspicion of brainstem death (BSD) to declaration of BSD. We identified 80 presumed brainstem dead patients over the study period. The mean age of this population was 35.9 years, and 67.5% were males. When formally asked for consent for organ donation (n = 49), 41 patients' relatives refused. The conversion rate was only 8.2%. The number of possible, potential and effective donors per million population per year were 127, 115.7 and 9.5,

respectively. The poor conversion rate of 8.2% suggests a huge potential for improvement. Family refusal in majority of cases reflects poor knowledge and thus warrants interventions at community level.

Ronanki VR et al., (2014)[87] has conducted a study by using semi structured questionnaire to collect information regarding each individual's awareness, knowledge, and perception regarding eye donation. Out of the 355 subjects interviewed, 192 (54%) were male and 163 (46%) were female. The mean age of the stakeholders was 35.9 years (SD ±16.1) and all the study subjects were literate. Ninety-three percent of subjects were aware of the concept of eye donation. Knowledge levels were similar among the teaching community and persons engaged in social service, but lower among students ($p < 0.05$). Among the stakeholders, there was considerable ambiguity regarding whether persons currently wearing spectacles or suffering from a chronic illnesses could donate their eyes. Older age group ($p < 0.001$), female gender ($p < 0.001$) and education ($p < 0.001$) were associated with increased knowledge levels. 82% of the subjects were willing to donate their eyes and this was unaffected by gender or geographical location (rural vs urban). The study concluded that awareness levels and willingness to donate eyes are high among the stakeholders in Srikakulam district in India.

3. NEED OF THE STUDY

Organ transplantation can treat a wide range of end-stage, life-threatening illnesses, including diseases of the heart, kidney, liver, lung, and pancreas. If enough organs were available, many thousands of patients, worldwide could benefit from transplantation medicine. Unfortunately, even in countries with high transplantation success rates, many patients in need will not receive a transplant because of the low rates of donation around the globe. Moreover, thousands more could benefit from a transplant should enough organs become available and the numerous restrictions applied to current waiting lists be relaxed.

Organ transplantation is an effective therapy for end-stage organ failure and is widely practiced around the world. According to World Health Organization (WHO), kidney transplants are carried out in 91 countries. Around 66,000 kidney donations, 21,000 liver donations and 6000 heart transplants were performed globally in 2005.[88] In India, the rate of organ donation is only 0.16 per million populations, compared to America's 26 and Spain's 35.[89] The scarcity of organ is practically a universal problem. Though many efforts were undertaken by the government to encourage the public enroute for donation of organs, the rate of organ donors has not paralleled the growing waiting list[90] and inadequate organ donation in India remains a major limiting factor for transplantation. There are several factors which could facilitate and hinder the general public to donate to combat the problem. Hence the present study is planned to conduct with an aim to explore the general publics perceived barriers and to access assess the awareness regarding organ donation among general publics from a rural part of India regarding organ donation.

4. AIM AND OBJECTIVES

Aim

To explore the general public Awareness, Beliefs and Barriers towards Organ Donation/ transplantation in Kumarapalayam.

Objectives

1. To Study the socio demographic details of study population
2. To assess the general community awareness and beliefs regarding organ donation/transplantation.
3. To determine general community perceived barriers regarding organ donation/transplantation.

5. METHODOLOGY

The present study was conducted in a rural town called Kumarapalaym in the Kongu region of Tamilnadu in India after obtaining prior ethical committee permission. The study was an observational cross-sectional type and Simple random Sampling Technique was used to select the samples. The study population included individuals above 18 years of age who were present in the house during the survey, out of which one person from each house was randomly interviewed. The study population understand either the local language Tamil or English. Data was collected by questionnaire method.

A pre-designed and pretested questions were adapted from various studies.[88,91-94] Details taken about awareness of organ donation, personal willingness to donate an organ for transplantation, and doubts to donation, family opinions towards donation were studied. Questionnaires were distributed without giving any prior information related to organ donation and procedure of organ donation. Participants were given sufficient time to fill up the questionnaire and filled questionnaires are collected back on the same day. The questionnaire was filled out by literate subjects. For illiterate subjects, the questions were asked through an interview in Tamil. The interviewer could only explain the meaning of questions for illiterate patients.

Sample size was determined by using the Raosoft sample size calculator using a margin of error of 5%, a confidence interval of 95%, a population size of 71594 people (Population size of Kumarapalayam), and an expected response of 50%. The minimum sample size estimated for the study was 383.

6. RESULTS

Table No: 1 Gender wise distribution of study population

s.no.	Gender	Number of participants (n=383)	Percentage
1	Male	221	57.70
2	Female	162	42.30

Figure No: 1 Gender wise distribution of study population

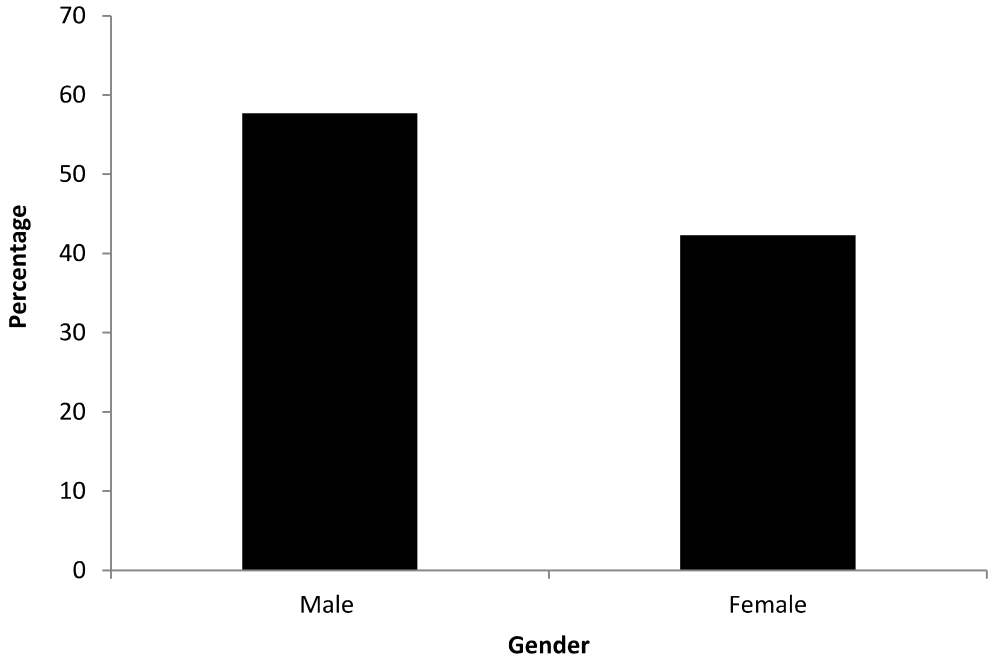


Table No: 2 Age wise distribution of study population

s.no.	Age (in years)	Number of participants (n=383)	Percentage
1	<25	62	16.19
2	25-40	126	32.90
3	41-55	93	24.28
4	56-70	78	20.37
5	>70	24	6.27

Figure No: 2 Age wise distribution of study population

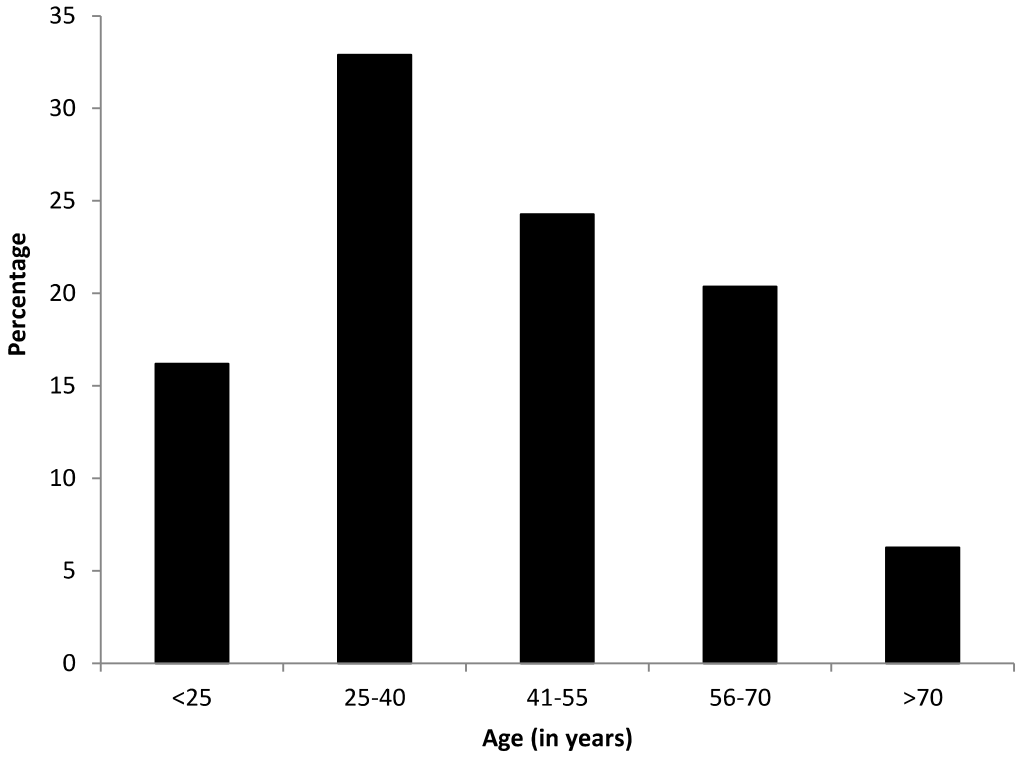


Table No: 3 Educational level of study population

s.no.	Education	Number of participants (n=383)	Percentage
1	Illiterate	73	19.06
2	Primary education	110	28.72
3	Secondary education	71	18.54
4	Pre-university	35	9.14
5	Degree and above	94	24.54

Figure No: 3 Educational level of study population

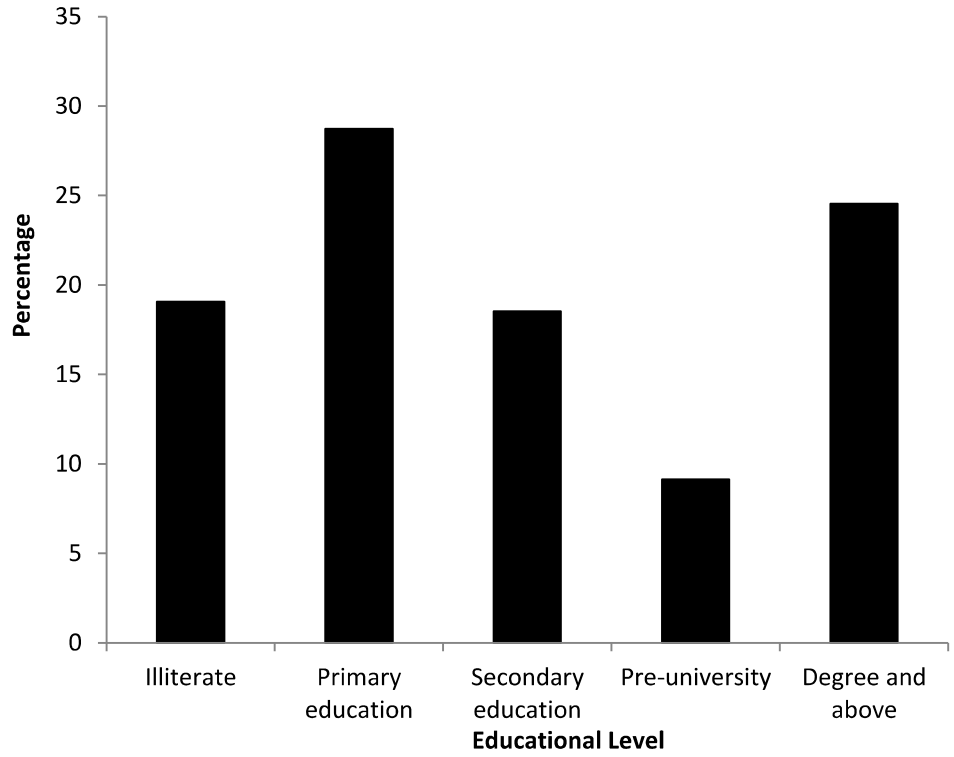


Table No: 4 Marital status of study population

s.no.	Marital status	Number of participants (n=383)	Percentage
1	Unmarried	84	21.93
2	Married	299	78.07

Figure No: 4 Marital status of study population

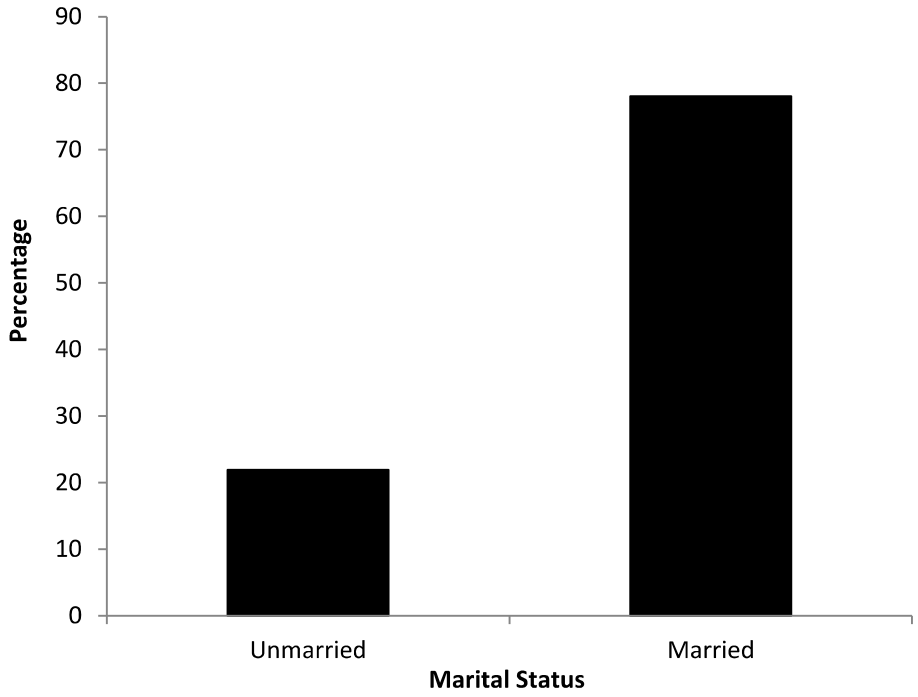


Table No: 5 Religion wise distribution of study population

s.no.	Religion	Number of participants (n=383)	Percentage
1	Hindu	261	68.15
2	Muslim	85	22.19
3	Christian	37	9.66

Figure No: 5 Religion wise distribution of study population

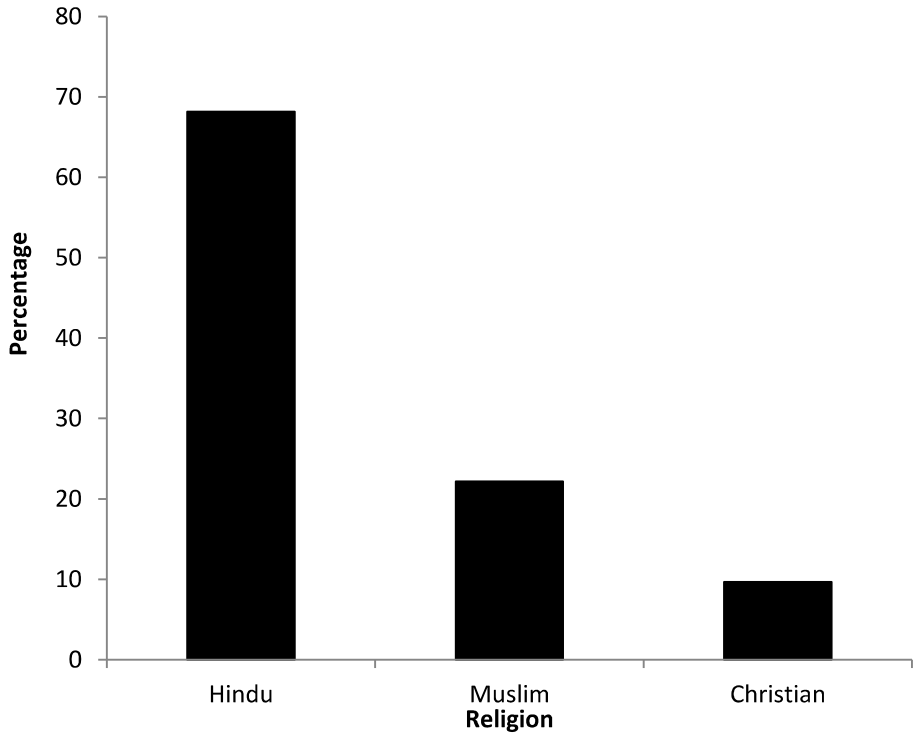


Table No: 6 Monthly Income of study population

s.no.	Income	Number of participants (n=383)	Percentage
1	<3000	143	37.34
2	3001-6000	116	30.29
3	6001-9000	15	3.92
4	>9000	109	28.46

Figure No: 6 Monthly Income of study population

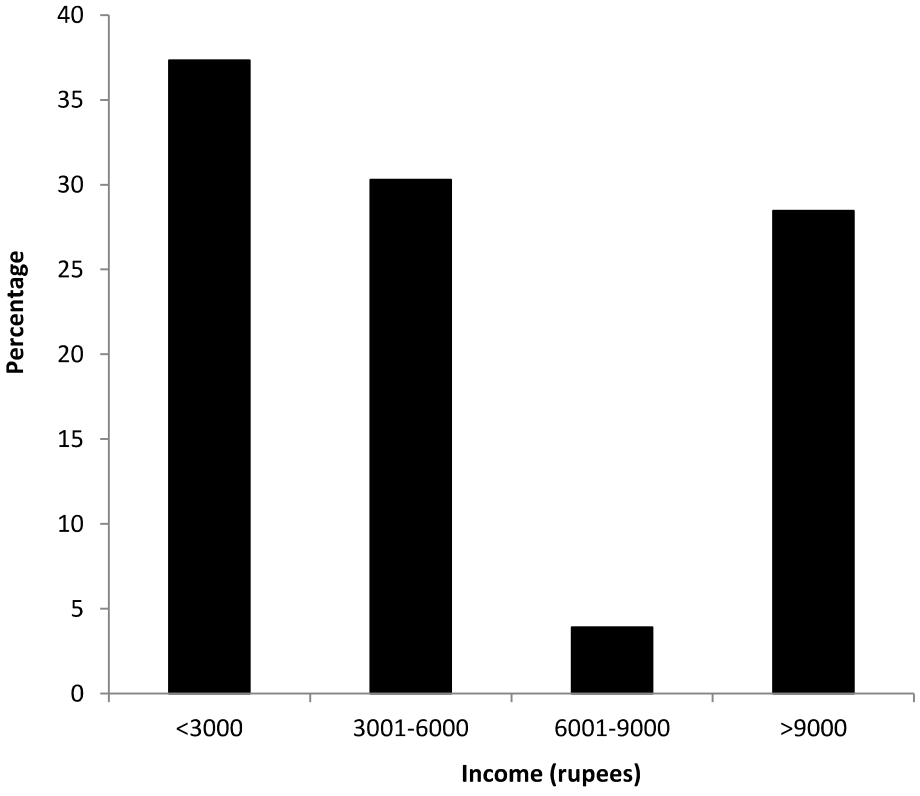


Table No: 7 Awareness and Beliefs towards Organ Donation (Answer to the Question: 1. Do you know any center where organ donation can be done?)

S. No	Attitudinal variable (Answer to the Question: 1. Do you know any center where organ donation can be done?)	Number of participants (n=383)	Percentage
1	Yes	85	22.19
2	No	298	77.81

Figure No: 7 Awareness, Beliefs and Barriers towards Organ Donation (Answer to the Question: 1. Do you know any center where organ donation can be done?)

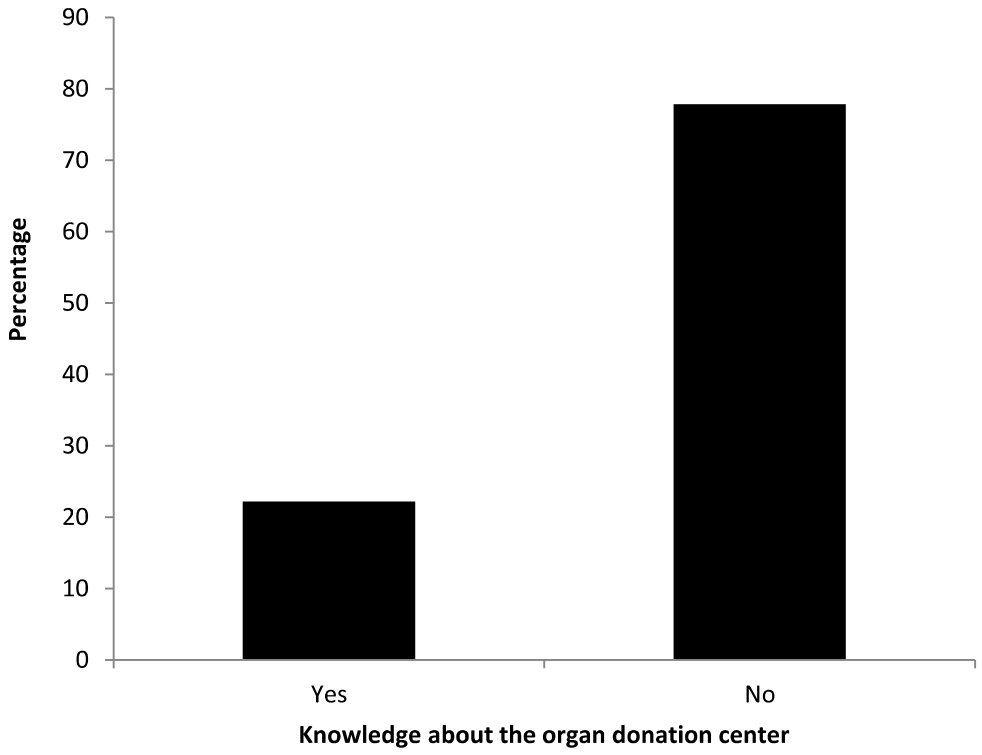


Table No: 8 Awareness, Beliefs and Barriers towards Organ Donation (Answer to the Question: 2. Do you know any hospital where organ transplant is done?)

S. No	Attitudinal variable (Answer to the Question: 2. Do you know any hospital where organ transplant is done?)	Number of participants (n=383)	Percentage
1	Yes	184	48.05
2	No	199	51.95

Figure No: 8 Awareness, Beliefs and Barriers towards Organ Donation (Answer to the Question: 2. Do you know any hospital where organ transplant is done?)

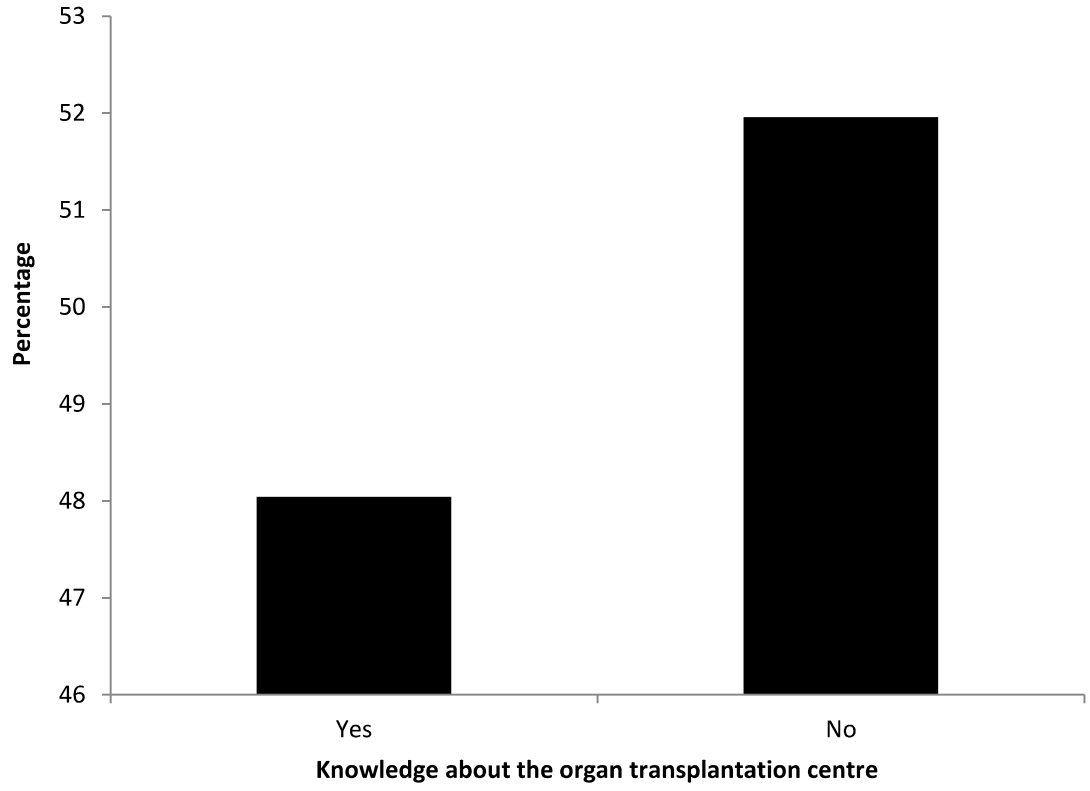


Table No: 9 Awareness and Beliefs towards Organ Donation (Answer to the Question: 3. Do you know anybody who has received any organ from someone?)

S. No	Attitudinal variable (Answer to the Question: 3. Do you know anybody who has received any organ from someone?)	Number of participants (n=383)	Percentage
1	Yes	62	16.19
2	No	321	83.81

Figure No: 9 Awareness and Beliefs towards Organ Donation (Answer to the Question: 3. Do you know anybody who has received any organ from someone?)

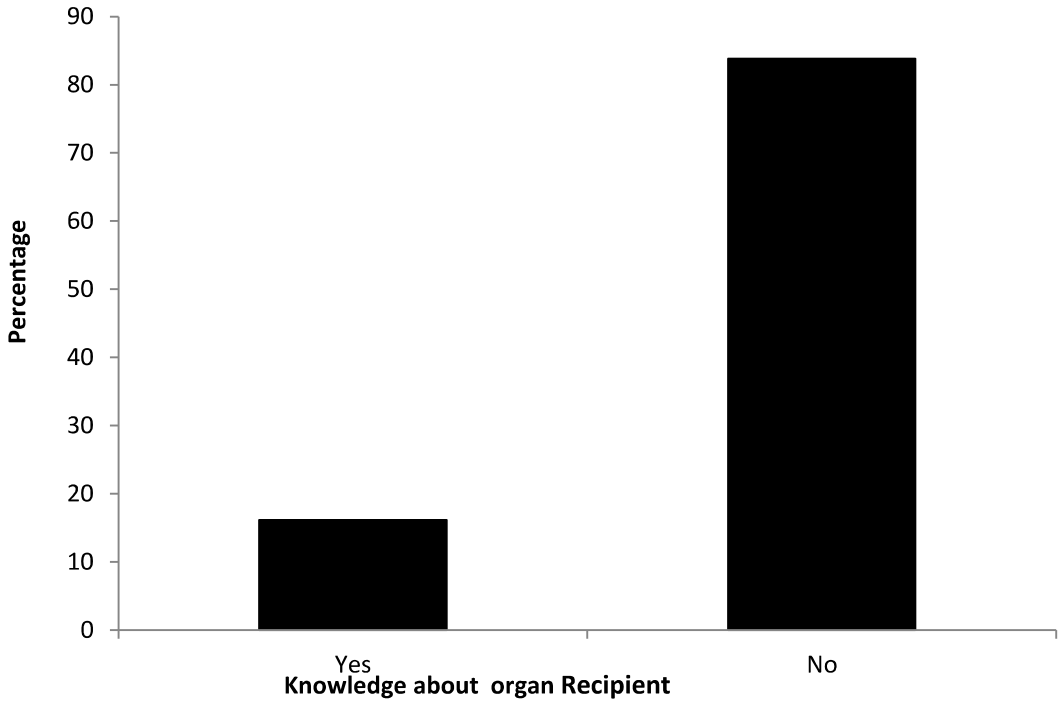


Table No: 10 Awareness and Beliefs towards Organ Donation (Answer to the Question: 4. Do you know anyone dead/alive who has donated any organ)

S. No	Attitudinal variable (Answer to the Question: 4. Do you know anyone dead/alive who has donated any organ)	Number of participants (n=383)	Percentage
1	Yes	89	23.24
2	No	294	76.76

Figure No: 10 Awareness and Beliefs towards Organ Donation (Answer to the Question: 4. Do you know anyone dead/alive who has donated any organ)

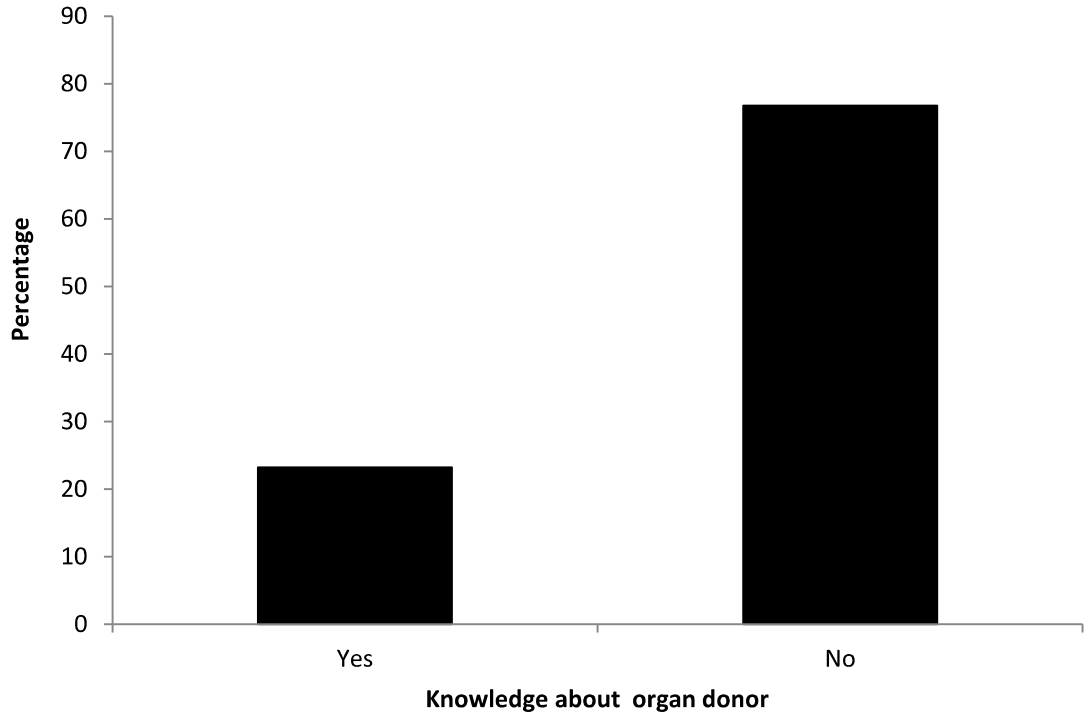


Table No: 11 Awareness and Beliefs towards Organ Donation (Answer to the Question: 5. Is there any law associated to organ donation in our nation?)

S. No	Attitudinal variable (Answer to the Question: 5. Is there any law associated to organ donation in our nation?)	Number of participants (n=383)	Percentage
1	Yes	28	7.31
2	No	63	16.45
3	I Don't know	292	76.24

Figure No: 11 Awareness and Beliefs towards Organ Donation (Answer to the Question: 5. Is there any law associated to organ donation in our nation?)

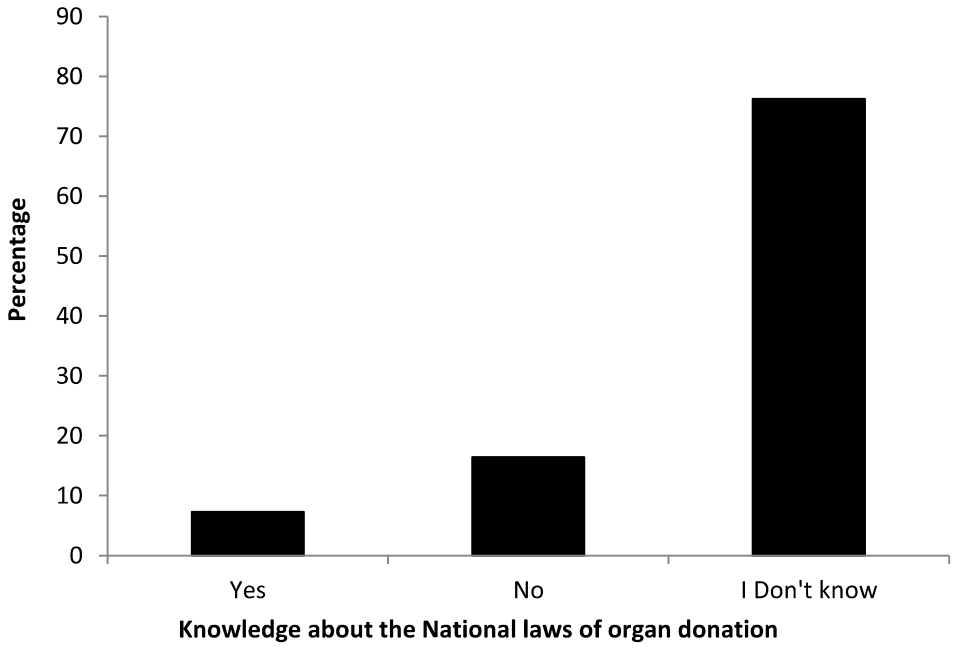


Table No: 12 Awareness and Beliefs towards Organ Donation (Answer to the Question: 6. Do you ever heard about brain death?)

S. No	Attitudinal variable (Answer to the Question: 6. Do you ever heard about brain death?)	Number of participants (n=383)	Percentage
1	Yes	246	64.22
2	No	137	35.78

Figure No: 12 Awareness and Beliefs towards Organ Donation (Answer to the Question: 6. Do you ever heard about brain death?)

Table No: 13 Awareness and Beliefs towards Organ Donation (Answer to the Question: 7. Is there any possibility of organ donation in the event of natural death?)

S. No	Attitudinal variable (Answer to the Question: 7. Is there any possibility of organ donation in the event of natural death?)	Number of participants (n=383)	Percentage
1	Yes	68	17.75
2	No	315	82.25

Figure No: 13 Awareness and Beliefs towards Organ Donation (Answer to the Question: 7. Is there any possibility of organ donation in the event of natural death?)

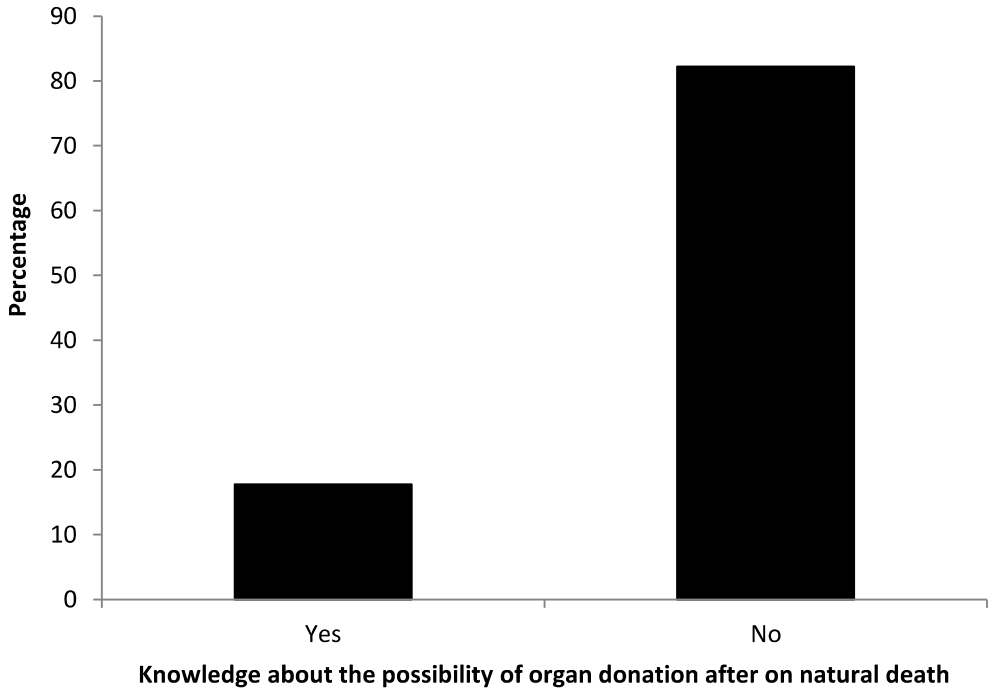


Table No: 14 Awareness and Beliefs towards Organ Donation (Answer to the Question: 8. Can organs be removed without permission of patient or family member?)

S. No	Attitudinal variable (Answer to the Question: 8. Can organs be removed without permission of patient or family member)	Number of participants (n=383)	Percentage
1	Yes	42	10.97
2	No	341	89.03

Figure No: 14 Awareness and Beliefs towards Organ Donation (Answer to the Question: 8. Can organs be removed without permission of patient or family member?)

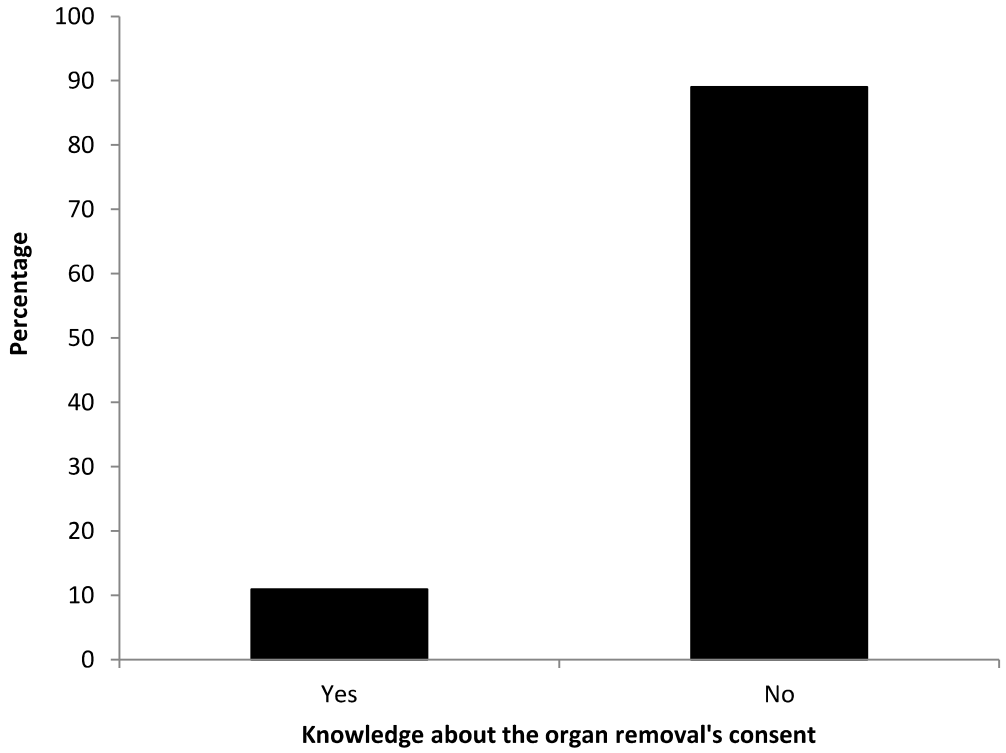


Table No: 15 Awareness and Beliefs towards Organ Donation (Answer to the Question: 9. Have you ever discussed regarding importance of organ donation with your family members?)

S. No	Attitudinal variable (Answer to the Question: 9. Have you ever discussed regarding importance of organ donation with your family members?)	Number of participants (n=383)	Percentage
1	Yes	198	51.69
2	No	185	48.31

Figure No: 15 Awareness and Beliefs towards Organ Donation (Answer to the Question: 9. Have you ever discussed regarding importance of organ donation with your family members?)

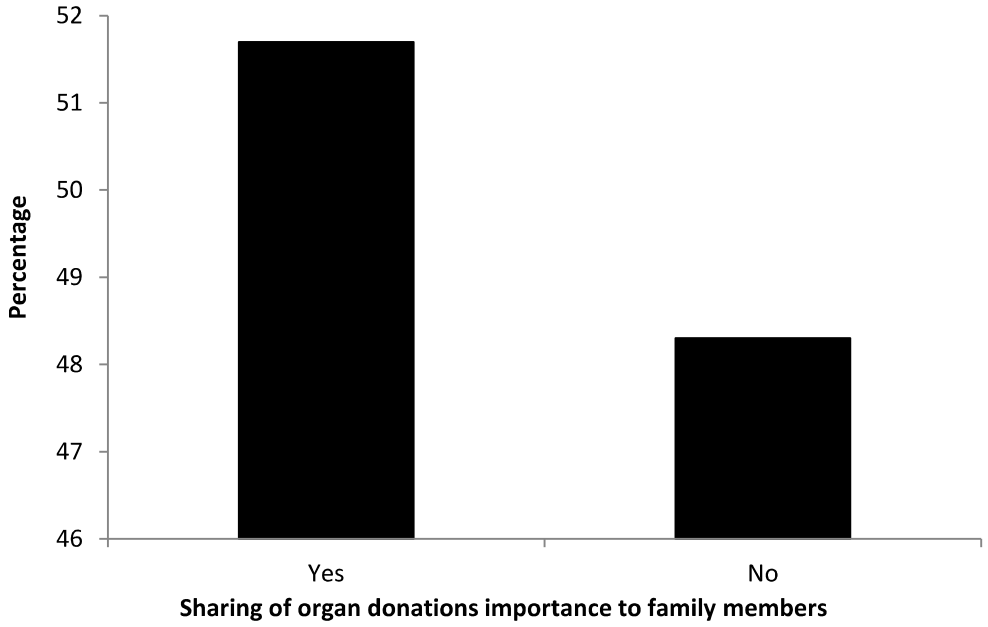


Table No: 16 Awareness and Beliefs towards Organ Donation (Answer to the Question: 10. Have you ever discussed regarding importance of organ donation with your friends?)

S. No	Attitudinal variable (Answer to the Question: 10. Have you ever discussed regarding importance of organ donation to your friends?)	Number of participants (n=383)	Percentage
1	Yes	208	54.30
2	No	175	45.69

Figure No: 16 Awareness and Beliefs towards Organ Donation (Answer to the Question: 10. Have you ever discussed regarding importance of organ donation with your friends?)

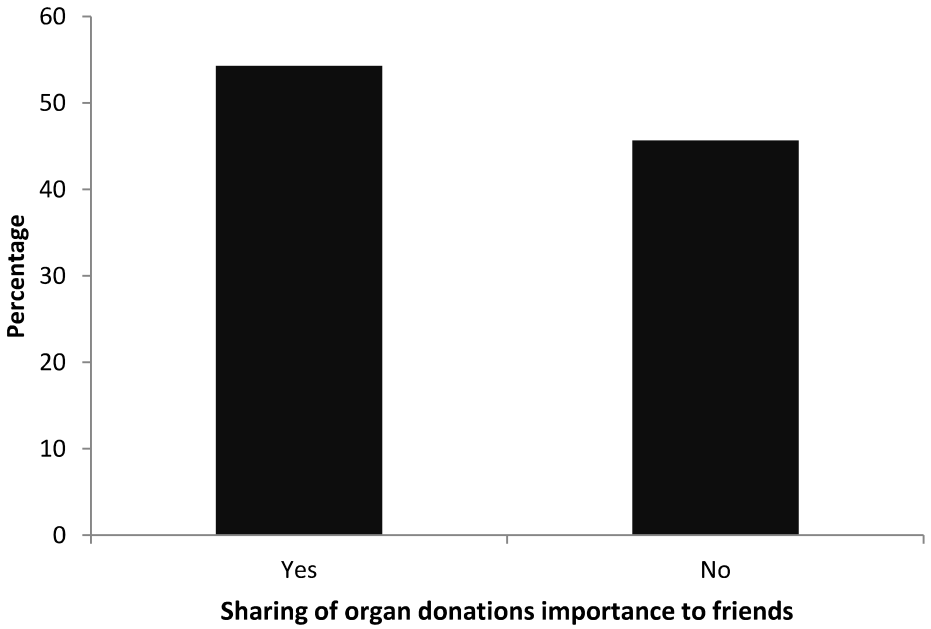


Table No: 17 Awareness and Beliefs towards Organ Donation (Answer to the Question: 11. Do you intend to donate your organs?)

S.No	Attitudinal variable (Answer to the Question: 11. Do you intend to donate your organs?)	Number of participants (n=383)	Percentage
1	Yes	203	53.00
2	No	114	29.76
3	Yes, but I would like to discuss with my family members	66	17.24

Figure No: 17 Awareness and Beliefs towards Organ Donation (Answer to the Question: 11. Do you intend to donate your organs?)

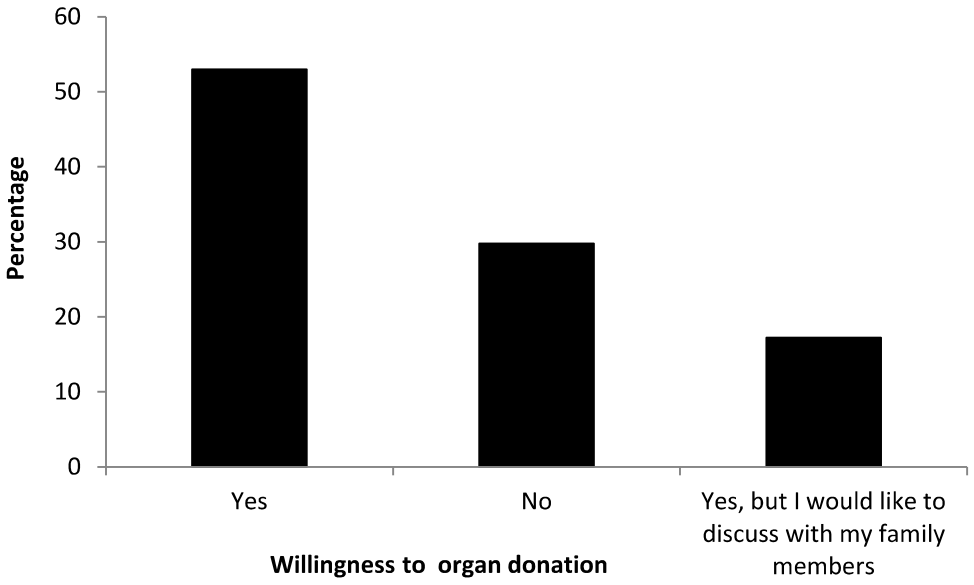


Table No: 18 Awareness and Beliefs towards Organ Donation (Answer to the Question: 12. Reason for being an organ donor?)

S. No	Attitudinal variable (Answer to the Question: 12. Reason for being an organ donor?)	Number of participants (n=269)	Percentage
1	I can help someone to live long/healthy life	128	33.42
2	I get monetary benefit	32	8.355
3	I get reward/empathy from others	22	5.744
4	It is my responsibility	87	22.72

Figure No: 18 Awareness and Beliefs towards Organ Donation (Answer to the Question: 12. Reason for being an organ donor?)

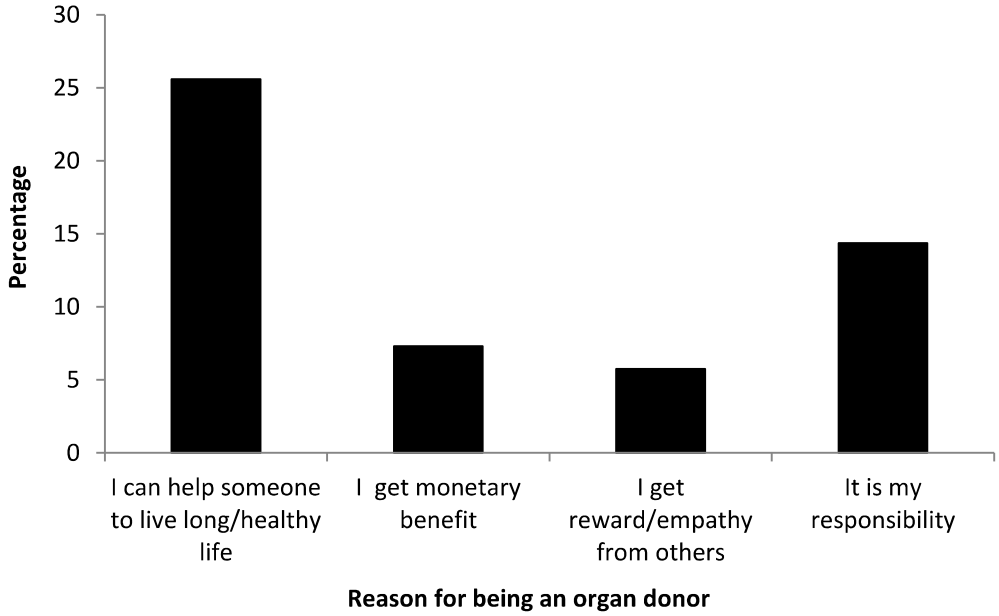


Table No: 19 Barriers towards Organ Donation (Answer to the Question: 13. Reason for being an live non-organ donor?)

S. No	Attitudinal variable (Answer to the Question: 13. Reason for being an live non-organ donor?)	Number of participants (n=383)	Percentage
1	Religious reasons	42	36.84
2	Affect my physical appearance	23	20.17
3	Fear of objection of family members	87	76.31
4	I believe in an after death life	28	24.56
5	Affect my health	96	84.21
6	Affect future	81	71.05
7	Fear	73	64.03

Figure No: 19 Barriers towards Organ Donation (Answer to the Question: 13. Reason for being an live non-organ donor?)

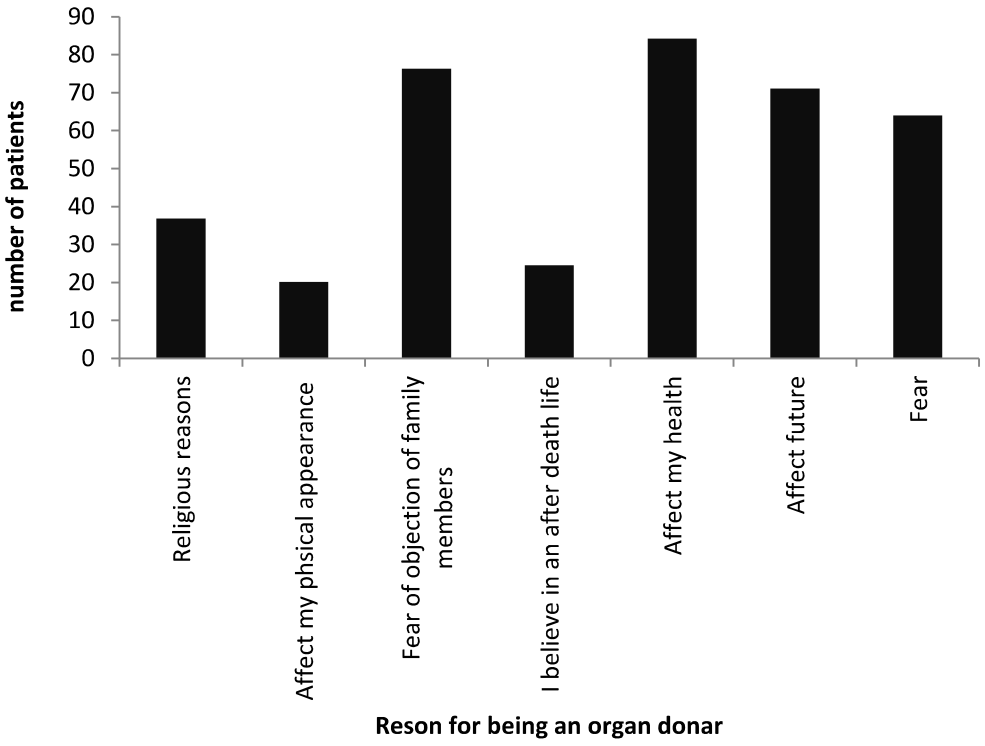


Table No: 20 Barriers towards Organ Donation (Answer to the Question: 14. Will you permit/ agree your family members to donate organs to unknown persons?)

S. No	Attitudinal variable (Answer to the Question: 14. Will you permit/ agree your family members to donate organs to unknown persons?	Number of participants (n=383)	Percentage
1	Yes	141	36.81
2	No	242	63.19

Figure No: 20 Barriers towards Organ Donation (Answer to the Question: 14. Will you permit/ agree your family members to donate organs to unknown persons?)

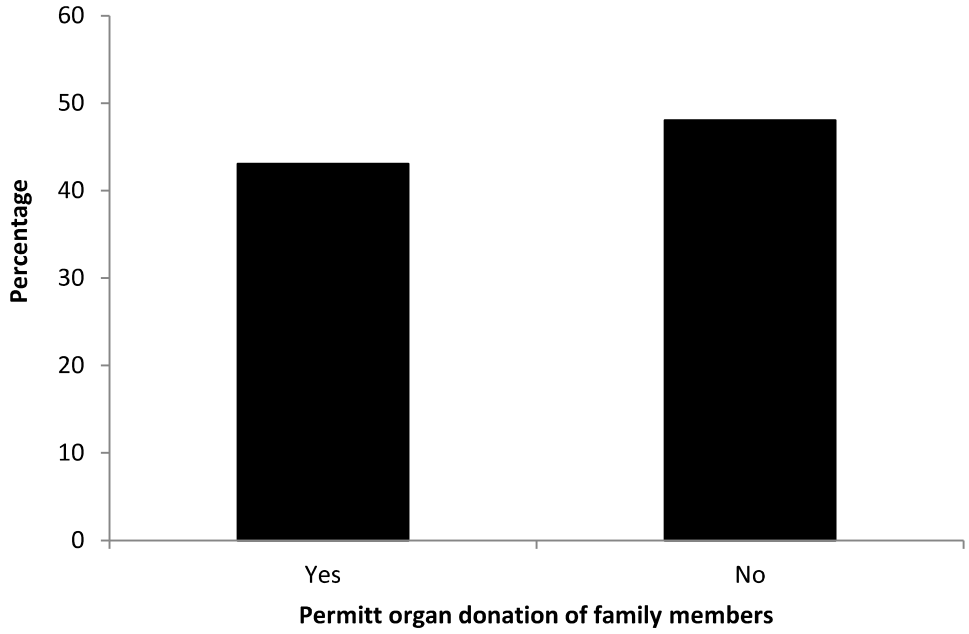


Table No: 21 Awareness and Beliefs towards Organ Donation (Answer to the Question: 15. Organs could be donated?)

S. No	Attitudinal variable (Answer to the Question: 15. Organs could be donated)	Number of participants (n=383)	Percentage
1	Kidney	343	89.55
2	Blood	343	89.55
3	Heart	89	23.23
4	Eyes	373	97.38
5	Liver	41	10.70
6	Skin	49	12.79
7	Bone marrow	29	7.57
8	Lungs	16	4.177
9	Others	41	10.70

Figure No: 21 Awareness and Beliefs towards Organ Donation (Answer to the Question: 15. Organs could be donated?)

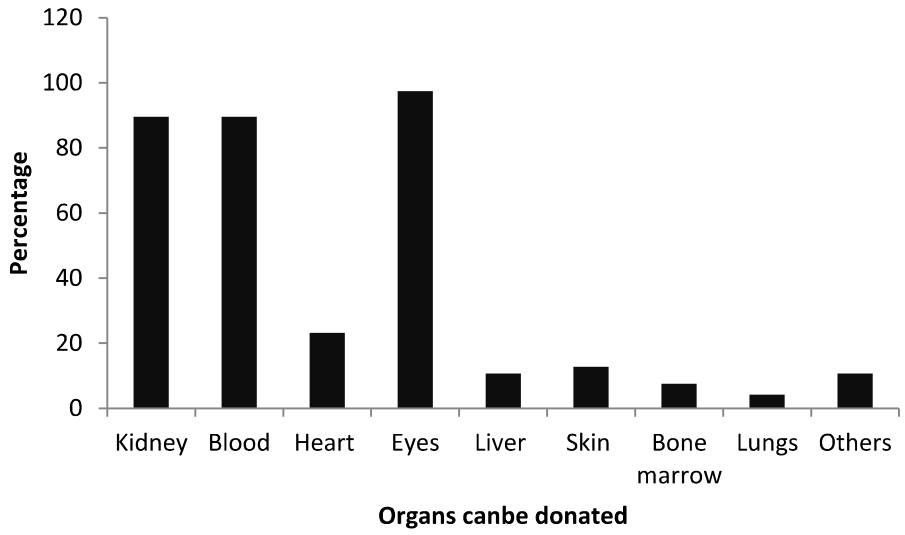


Table No: 22 Awareness and Beliefs towards Organ Donation (Answer to the Question: 16. Who give consent for living donation?)

S. No	Attitudinal variable (Answer to the Question: 16. Who give consent for living donation?	Number of participants (n=383)	Percentage
1	Donor	160	41.77
2	Family Members	215	56.13
3	Friends	8	2.08

Figure No: 22 Awareness and Beliefs towards Organ Donation (Answer to the Question: 16. Who give consent for living donation?)

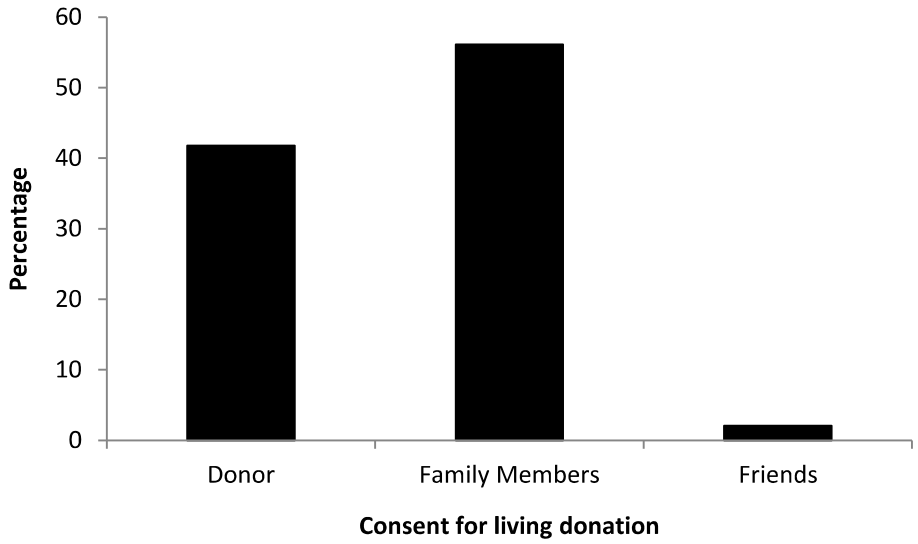


Table No: 23 Awareness and Beliefs towards Organ Donation (Answer to the Question: 17. Who give consent when donor is dead?)

S. No	Attitudinal variable (Answer to the Question: 17. Who give consent when donor is dead?	Number of participants (n=383)	Percentage
1	Family Members	228	59.53
2	Friends	0	0
3	No one	0	0
	I don't know	155	40.46

Figure No: 23 Awareness and Beliefs towards Organ Donation (Answer to the Question: 17. Who give consent when donor is dead?)

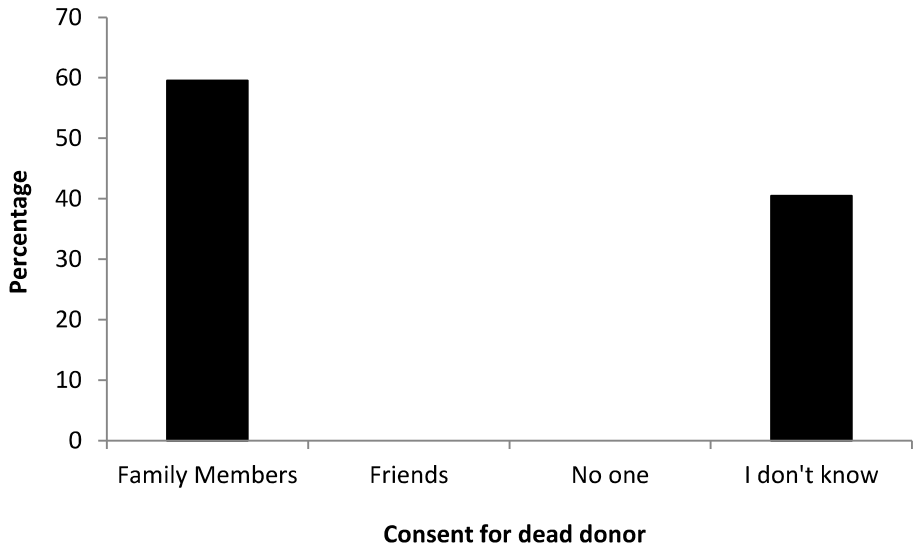


Table No: 24 Awareness and Beliefs towards Organ Donation (Answer to the Question: 18. Will you accept organ donation from other community/religion when it is necessary?)

S. No	Attitudinal variable (Answer to the Question: 18. Will you accept organ donation from other community/religion when it is necessary?	Number of participants (n=383)	Percentage
1	Yes	334	87.21
2	No	49	12.79

Figure No: 24 Awareness and Beliefs towards Organ Donation (Answer to the Question: 18. Will you accept organ donation from other community/religion when it is necessary?)

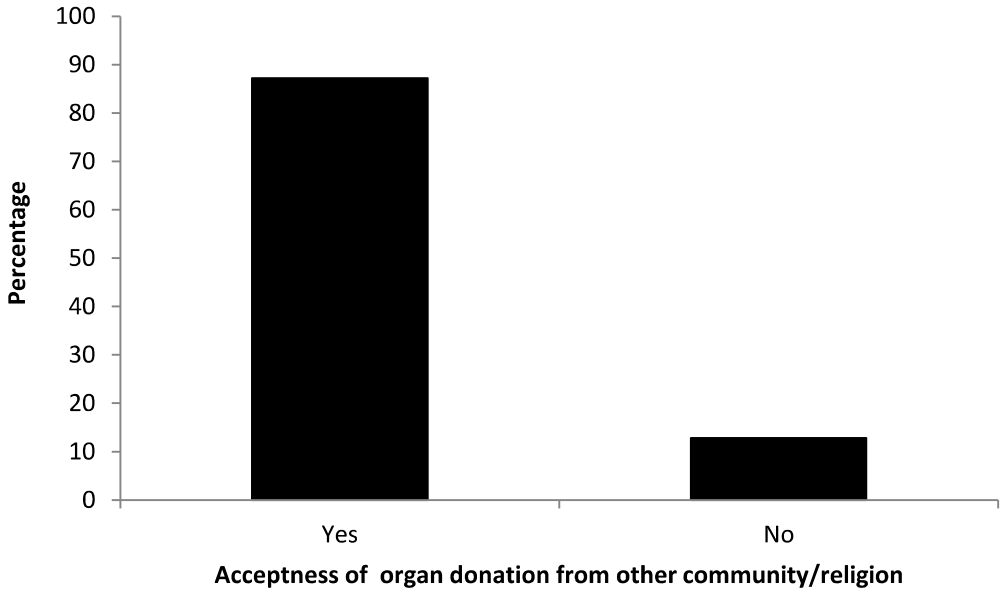


Table No: 25 Awareness and Beliefs towards Organ Donation (Answer to the Question: 19. Will you accept organ donation from other community/religion when it is necessary)

S. No	Attitudinal variable (Answer to the Question: 19. Will you accept organ donation from other community/religion when it is necessary?	Number of participants (n=383)	Percentage
1	Yes	223	58.23
2	No	160	41.77

Figure No: 25 Awareness and Beliefs towards Organ Donation (Answer to the Question: 19. Will you accept organ donation from other community/religion when it is necessary)

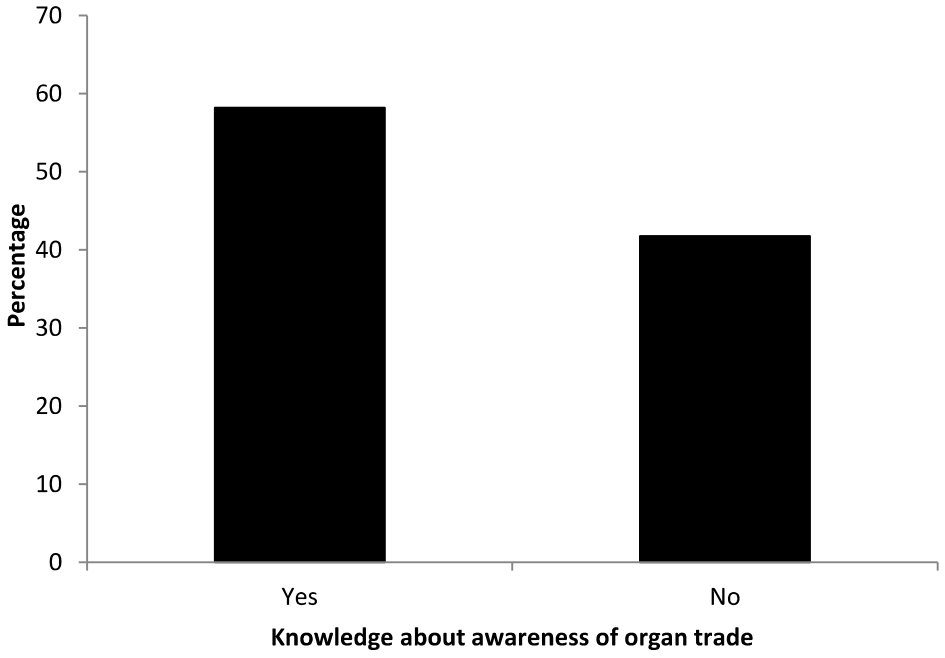
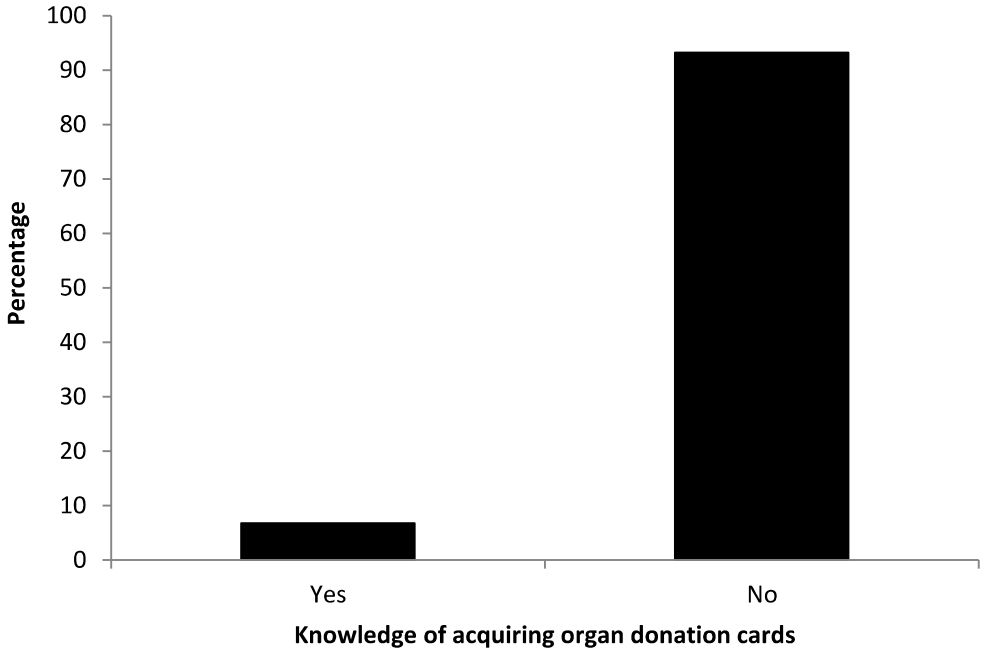


Table No: 26 Awareness and Beliefs towards Organ Donation (Answer to the Question: 20. Do you aware selling of organs for money (organ trade)?)

S. No	Attitudinal variable (Answer to the Question: 20. Do you aware selling of organs for money (organ trade)?	Number of participants (n=383)	Percentage
1	Yes	26	6.78
2	No	357	93.21

Figure No: 26 Awareness and Beliefs towards Organ Donation (Answer to the Question: 20. Do you aware selling of organs for money (organ trade)?)



7. DISCUSSION

Organ transplantation is the most preferred treatment modality for end-stage organ disease and organ failure. It offers a better quality of life with a better survival benefits. Therefore, the magnitude of organ retrieval is extremely important. The success of retrieval is hugely dependent on the levels of knowledge and attitude of the people. Health care professionals play a vital role in imparting positive knowledge towards organ donation among the people.

Study aimed to determine the awareness level toward organs organ donation in the general publics of kumarapalayam. A total of 383 respondents participated in the study, out of which 221 (57.70%) were males and 162 (42.30%) were females. 299 (78.07%) were married. Among the study population, 28.72% were completed Primary education and 73(19.06%) were Illiterate. Majority (32.90%) were in the age range of 25-40 years and majority of them Hindu (68.15). In the study population, 298 (77.81%) respondents do not know organ donation centers and 184 (48.05%) only knew organ transplantation centers. Only 62 (16.19%) respondents knew the persons those received any organ from someone. 89(23.24%) knew the persons dead/alive who has donated any organs. Only few people 28 (7.31 %) were aware about law related organ donation in our country. 68 (17.75%) respondents positively answered possibility of organ donation in the event of natural death. 341(89.03%) respondents answered that organs can't removed without permission of patient or family member. 185 (48.31%) respondents not discussed regarding importance of organ donation with your family members. Similarly, only 208 (54.30%) respondents were discussed regarding importance of organ donation with their friends. 203(53.00%) respondents have intention to donate organs. Similar another study conducted in New Delhi where 61.59% people were ready to donate their organs after death[95] while study conducted in college students where 75.3% of the study population said positive response for

their own organ to be donated. Similar finding has been reported in a study done by Odusanya et al.,[96] wherein 30% respondents expressed willingness for self-organ donation. In another study conducted in China by Zhang et al.,[97] 49.8% respondents indicated they would be willing to be living organ donors, A still higher response was observed in a study in Ohio wherein 96% of respondents expressed favorable attitudes toward donation.[98]

96(84.21%) thinking that live organ donation affect their health and 81(76.31%) have fear of objection of family members to donate live organ donation. 81(71.05%) respondents answered that live organ donation affect future. Other barriers were religious reasons 42(36.84%), affect physical appearance 23(20.17%), believe in an after death life 28 (24.56 %) and fear 73(64.03%). 141(36.81%) respondents permit/ agree their family members to donate organs to unknown persons. Maximum awareness was found to be for eye donation (97.38%) followed by kidney donation (89.55 %), Blood (89.55%), Heart (23.23%), Skin (12.79%) and Bone marrow (7.57%). According to a study done among Medical students in Chitradurga, India,[99] only few (62.9%) knew about live kidney donation whereas subject of the present study had better knowledge about live kidney donation Majority (56.13) of them answered that for live donation donors consent is required and 155(40.46%) respondents don't know procedures to get consent when donor is dead.

58.23% respondents are ready to accept organ donation from other community/religion when it is necessary. 93.21% respondents do not aware of selling of organs for money (organ trade).

All focus group research has limited generalizability, so the findings reported here cannot be applied beyond the communities where this study took place. Potential selection bias is another key limitation, since focus group participants obviously had an interest in organ donation and transplantation. Despite these limitations, the use of volunteer

focus groups remains a relevant methodology for collecting in-depth information that is rarely possible to obtain through other approaches.

8. CONCLUSION

This study makes a substantial contribution to existing research on organ donation. This study found that awareness on organ donation among people in kumarapalayam is lacking and there exists significant gaps in their knowledge on the same and also this study identifies several areas where educational interventions are necessary. In conclusion, the study showed a considerable number of participants willing to donate their organs. In countries like India, there is a significant demand for organ donation in spite of availability of organs. The results of the study revealed the urgent need for addressing this knowledge gap by conducting awareness sessions in medical schools and also engage them in discussions during mass campaigns.

A well-organized approach is required to raise awareness among the youth about various aspects of organ donation which is necessary to eliminate the setbacks that affect the rate of availability of donor organs. Motivational messages and facts are some of the means of intervention to bring about changes regarding perceptions and intentions about organ donation among the students. Other educational tools such as advertisements, campaigns, exhibitions, and lectures can improve the awareness and attitude about organ donation among the population. Since media is the major role in communication these days, they should take up the initiative of broadcasting the legislative laws that are involved in the process of organ donation. Future research would benefit from more sophisticated analysis of the reasons for the low numbers of organ donations worldwide.

9. REFERENCES

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PATIENT INFORMATION FORM

Dear participant,

We are students of J.K.K.NATTRAJA COLLEGE OF PHARMACY currently conducting a project entitled" A STUDY ON EXPLORATION OF AWARENESS, BELIEFS AND BARRIERS TOWARDS ORGAN DONATION AMONG PEOPLE IN KUMARAPALAYAM". As a part of project, we need to collect data including the general community awareness and beliefs regarding organ donation/transplantation. However, no identifiable personal data will be disclosed.

Thank you very much for your kind participation.

CONSENT FORM

I, _____ have read and understand the above information. I have agreed to allow my data to be utilised for the project work.

_____ _____

Signature of participant Date

Translated by:

ANNEXURE – I

Data Entry Form

1. **Name of the Patient**

2. **Address**

3. **Phone no.**

4. **Gender**
   a. Male
   b. Female

5. **Age in years**
   a. <25 years old
   b. 25-40 years old
   c. 41-55 years old
   d. 56-70 years old
   e. >70 years old

6. **Education Level**
   a. Illiterate
   b. Primary education
   c. Secondary education
   d. Pre-university

e. Degree and above

7. Marital status

a. Married

b. Unmarried

8. Baseline LDL levels

a. Religion

b. Hindu

c. Muslim

d. Christian

9. Monthly Income

a. <3000

b. 3001-6000

c. 6001-9000

d. >9000

ANNEXURE – II

Patient ID:

J.K.K.Nattraja College of Pharmacy, Kumarapalayam

Knowledge About Organ Donation

1. Do you know any center where organ donation can be done?
   - Yes
   - No

2. Do you know any hospital where organ transplant is done?
   - Yes
   - No

3. Do you know anybody who has received any organ from someone?
   - Yes
   - No

4. Do you know anyone dead/alive who has donated any organ?
   - Yes
   - No

5. Is there any law associated to organ donation in our nation?
   - Yes
   - No

6. Do you ever heard about brain death?
   - Yes
   - No

7. Is there any possibility of organ donation in the event of natural death?
    - Yes
    - No

8. Can organs be removed without permission of patient or family member?
    - Yes
    - No

9. Have you ever discussed regarding importance of organ donation with your family members
    - Yes
    - No

10. Have you ever discussed regarding importance of organ donation with your friends?
    - Yes
    - No

11. Do you intend to donate your organs?
    - Yes
    - No
    - Yes, but I would like to discuss with my family members

12. If answer is 'yes', specify the reason for being an organ donor
    - I can help someone to live long/healthy life
    - I can get monitory benefit
    - I get reward/empathy from others
    - It is my responsibility

13. If answer is 'No', specify the reason for being an non-organ donor

- Religious reasons
- Affect my phsical appearance
- Fear of objection of family members
- I believe in an after death life
- Affect my health
- Affect future
- Fear

14. Will you permit/ agree your family members to donate organs to unknown persons?

- Yes
- No

15. Organs could be donated?

- Kidney
- Blood
- Heart
- Eyes
- Liver
- Skin
- Bone marrow
- Lungs
- Others

16. Who give consent for living donation?

- Donor
- Family members
- Friends

17. Who give consent when donor is dead?

- Family members
- Friends
- No one
- I don't Know

18. Will you accept organ donation from other community/religion when it is necessary?

- Yes
- No

19. Do you aware selling of organs for money (organ trade)?

- Yes
- No

20. Do you know where to obtain organ donation cards?

- Yes
- No